

PSYCHOSOCIAL REHABILITATION FOR SCHIZOPHRENIA IN SOUTH AFRICA

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by: Carrie Brooke-Sumner

DEVELOPING A
COMMUNITY
BASED
APPROACH TO
PROMOTE
RECOVERY IN
DR KENNETH
KAUNDA
DISTRICT

**Psychosocial rehabilitation for schizophrenia: developing a
community-based approach to promote recovery in Dr Kenneth
Kaunda district, South Africa**

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Declaration

I certify that the work in this thesis entitled “Psychosocial rehabilitation for schizophrenia: developing a community-based approach to promote recovery in Dr Kenneth Kaunda district, South Africa” has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree to any other university or institution other than the University of KwaZulu-Natal.

I also certify that the thesis is an original piece of research and it has been written by me. Any help and assistance that I have received in my research work and the preparation of the thesis itself have been appropriately acknowledged.

In addition, I certify that all information sources and literature used are indicated in the thesis.

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Date: March 2016.

Dedication

This work is dedicated to my husband Pete, who has supported me in every way in getting the work completed, and to my son Jack and daughter Eva who have helped me to put everything into perspective and to achieve balance in my life. It is also dedicated to my mother and father, who both in their different ways have encouraged me to follow an academic career and to find a career path that allows me to work to improve the lives of others.

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Abstract

Background: Schizophrenia, a chronic and severe mental illness, contributes significantly to the global burden of disease and disability. In addition to biomedical treatment, service users with schizophrenia require psychosocial rehabilitation (PSR) which comprises a variety of psychosocial interventions aimed at promoting recovery. In low and middle income countries (LMIC) a task-sharing approach to provision of PSR is recommended, however there are few intervention studies from LMIC and none from a low-resource South African context. This doctoral work addressed this gap in evidence through developing a contextually appropriate, task-shared, manualised support group intervention for PSR in Dr Kenneth Kaunda district, delivered by auxiliary social worker (ASW) facilitators. Development of the intervention was guided by the UK Medical Research Council (MRC) framework for complex interventions. Given the requirement for intersectoral collaboration for scale-up of task-shared PSR indicated in South Africa's National Mental Health Policy, this doctoral work also investigated challenges and ways forward for addressing lack of intersectoral collaboration as a key structural barrier to scale up.

Methods: Firstly, a systematic literature review of feasibility and acceptability of psychosocial interventions for schizophrenia from LMIC was conducted. Factors promoting acceptability and feasibility were identified through a meta-synthesis of qualitative and quantitative data. Secondly, in-depth semi-structured interviews were conducted with 9 service users with schizophrenia and their 9 caregivers. Thematic analysis was used to understand their perceptions of illness and specific needs. These two aspects of formative research informed the development of the intervention and corresponding materials (Training Manual, Facilitator Guide). Thirdly, a preliminary pilot group with 6 members was run between September and December 2013 with 2 ASW facilitators. For an initial formative evaluation, in-depth qualitative interviews with group members were conducted at baseline, midpoint and endpoint

(18 interviews in total). Endpoint interviews were also conducted with facilitators. Framework analysis was used to identify evidence of acceptability and feasibility. Fourthly, in-depth qualitative interviews were conducted with 24 representatives from different sectors involved in the provision of PSR (Department of Health, Department of Social Development, Non-Governmental Organisations). Framework analysis was conducted to investigate challenges to intersectoral collaboration and potential for addressing these challenges.

Results: The systematic review and qualitative research with service users and caregivers produced recommendations for improving acceptability and feasibility including: using materials appropriate for participants educational level and language; understanding traditional explanatory models of illness and significance of religion as a coping strategy; and addressing specific identified needs (e.g. for psychoeducation, adherence support, coping skills for conflict, coping skills for stigma and discrimination, provision of income generation). In the qualitative process evaluation service users and facilitators reported improvements in illness knowledge, self-care and reduced social isolation. Recommendations for improvement of the intervention included further mobilisation of families and caregivers; allocation of more facilitator and supervisor time to allow for home visits; and involvement of a partner organisation to further develop the income generation aspect of the intervention. The investigation into intersectoral collaboration for PSR provided recommendations for improving this working strategy including: role clarification and building capacity to meet these roles within each sector; providing for a focal person to coordinate collaboration and fulfil a case management role for individual patients; improving communication and referrals between sectors; and ensuring appropriate resource allocation for PSR at community level.

Conclusion: The contextually appropriate intervention described in this work shows evidence of acceptability and feasible delivery by ASWs in a task-shared model. The intervention warrants further testing at a larger scale, including with objective measures of symptoms,

disability and functioning. This may be achieved through further piloting and a randomised controlled trial. However, for this to be possible, crucial barriers to feasibility identified in the study need to be addressed. These relate primarily to appropriate allocation of resources for the provision of a PSR service, in particular to enable appropriate inputs of ASW and supervisor time for more comprehensive support of service users and mobilisation of families. This will rely on appropriate intersectoral collaboration and leverage of existing resources, which will necessitate considerable political will.

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Acronyms

ACT	Assertive Community Treatment
ASW	Auxiliary Social Worker
CBR	Community-based Rehabilitation
CBO	Community-based Organisation
CMD	Common Mental Disorder
DOH	Department of Health
DOSD	Department of Social Development
HIC	High Income Countries
ICM	Intensive Case Management
ICDM	Integrated Chronic Disease Management
LMIC	Low and Middle Income Countries
MRC	Medical Research Council
NGO	Non-governmental Organisation
PHC	Primary Health Care
PSR	Psychosocial Rehabilitation
RCT	Randomised Controlled Trial
SES	Socio-economic Status
WHO	World Health Organisation
WPA	World Psychiatric Association

Chapter 1 Introduction and Background

Background – Global Mental Health

Mental illness in the form of either common mental disorders (CMD, e.g., depression, anxiety) or severe mental disorders (e.g., schizophrenia, bipolar mood disorder) places a significant burden on those with the illness themselves, family members and other caregivers. These disorders contributed 183 million Disability Adjusted Life Years (DALYs) according to the Global Burden of Disease Study 2010 and are the leading cause of years lost to disability (Murray et al., 2012; Whiteford et al., 2013). The financial costs of mental illnesses to Low and Middle Income Countries (LMIC) have been projected to increase from 870 billion USD in 2010 to 2113 billion USD in 2030 (Bloom et al., 2011).

Globally, funding for mental health services has historically been notably low in relation to the burden of disease (Jenkins et al., 2011b; Saraceno et al., 2007; Saxena et al., 2007). This is particularly acute in LMIC, in which the 2014 WHO Atlas Project found yearly expenditure on mental health services to be less than US\$2 per capita, primarily dedicated to inpatient services, compared with high income countries (HIC) which expend up to US\$50 per capita on the required services (WHO, 2015). Mental health has been absent from the focus of programmes of the World Bank (Lund, 2012) and other development organisations. Between 2007 and 2013, although development assistance globally for mental health did increase, it still constitutes barely 1% of the overall development assistance for health, and is directed mostly to fund the non-public sector (e.g., Non-Governmental Organisations, NGOs) as opposed to the public sector for integration into public health systems (Gilbert et al., 2015). Reasons for the small resource allocation for mental health include competing health priorities (notably communicable diseases like malaria, HIV, TB), and the fact that allocation of resources is often more of a political issue than based on population needs (Tomlinson & Lund, 2012). There has also been an enduring opinion among international donors and national health policy makers

that there is little “return on investment” for mental health in terms of promoting development (Saraceno et al., 2007).

More recently momentum for greater investment in mental health is being generated through recognition of links between mental disorders and poverty and comorbidity with communicable diseases such as HIV (Jenkins et al., 2011a). There is a growing movement of donors and funding agents (and consequently, researchers and NGOs), clinical practitioners, advocates and service users who share objectives of improving mental health and development and providing services that support people’s right to mental health. Globally this has been signalled by the Lancet 2007 series on Global Mental Health (Jacob et al., 2007; Patel et al., 2007a; Prince et al., 2007; Saraceno et al., 2007; Saxena et al., 2007) and the follow-up 2011 Lancet series on Global Mental Health (Drew et al., 2011; Eaton et al., 2011; Kakuma et al., 2011; Kieling et al., 2011; Lund et al., 2011; Tol et al., 2011), the PLoS Medicine series on packages of care for mental disorders (Benegal et al., 2009; Flisher et al., 2010; Mari et al., 2009; Mbuba & Newton, 2009; Patel et al., 2009; Prince et al., 2009), the WHO mhGAP intervention guide (WHO, 2010), the establishment of the Movement for Global Mental Health (www.globalmentalhealth.org) and the more recent Mental Health Innovation Network (mhinnovation.net). The World Health Assembly also adopted the Comprehensive Mental Health Action Plan 2013 – 2020 calling for integrated mental health and social care services in communities (WHO, 2013). Although mental health was not mentioned at all in the Millennium Development Goals, leading to a lack of focus of donor and government resources and attention to the area, the Sustainable Development Goals which have recently been adopted include a target for mental health and wellbeing (Buse & Hawkes, 2015; Thornicroft & Patel, 2014). It is hoped that this will encourage the required flow of resources to the neglected issue of mental wellbeing.

The impact of schizophrenia

Schizophrenia is a severe, chronic mental disorder with lifetime prevalence estimated at 4.0 per 1000 globally, however estimates vary by site (McGrath et al., 2008). People with schizophrenia have a greatly shortened life expectancy (approximately 20 years below the general population) and this mortality gap is thought to have increased in past decades as people with schizophrenia have not seen the benefits of increasing life expectancy evident in the general population (Laursen et al., 2014). Evidence from HIC indicates people with schizophrenia are considerably more likely to die early, particularly from “unnatural” causes such as substance abuse (Reininghaus et al., 2015). HIC studies have also shown people with schizophrenia to be three times more likely to develop diabetes (Peet, 2004) and twice more likely to have cardiovascular disease (Gupta & Craig, 2009) compared to the general population. Linked to this, evidence from one LMIC (South Africa) points to high risk of early mortality for people with severe mental illness due to extremely low rates of screening for diabetes and cardiovascular disease in this patient group (Saloojee et al., 2014).

Schizophrenia contributes 15.2 million DALYs to the burden of disease in LMIC (Collins et al., 2011). A seemingly low proportion (7.4%) of the disease burden within the mental and substance use disorder category is due to schizophrenia (Whiteford et al., 2013). However there is recognition that severe mental illnesses can be highly disabling and considerably undermine a person’s ability to function in their social environment. Schizophrenia ranks 18th out of all disorders studied in contribution to Years Lived With Disability (YLD) (Whiteford et al., 2013). Given the relatively low prevalence of the disorder, this high rank reflects the allocation of the highest disability rating to schizophrenia (out of all health disorders studied) in the Global Burden of Disease study (Whiteford et al., 2013) (YLDs are calculated as the product of prevalent cases by disability weighting). Additionally, providing services for schizophrenia

exerts a high cost to health services both in HIC and LMIC (Bloom et al., 2011; Saraceno et al., 2005) including through frequent rehospitalisations of service users when community-based services are inadequate.

Crucially, the true impact of this disease (on individual's functioning and on the family and caregivers) are not effectively accounted for in the commonly used DALY measurement. The severity of the impact of schizophrenia is evident in its recognition as a priority condition to be addressed on human rights and social justice grounds (Chisholm & WHO, 2005; Collins et al., 2011; Patel, 2015). The nature of the illness means schizophrenia contributes a low number to total deaths globally, and interventions (biomedical or psychosocial) do not lead to reductions in mortality or to cure of the disorder. This has meant interventions for schizophrenia have been assessed as less cost effective than, for example, antiretroviral drugs (Patel, 2015). Prioritising interventions for schizophrenia has therefore been unattractive in the resource-constrained healthcare environment. Recent calls to action highlight the need to look beyond mortality reduction and cost-effectiveness and include a focus on "the enormous health, economic and social hardships . . . and some of the worst instances of human rights abuse witnessed in modern times" (Patel, 2015), p. 2, to bolster progress on service provision for schizophrenia. The role of the rapidly changing socioeconomic and cultural environment in sub-Saharan Africa (e.g., rapid urbanisation, high levels of migration, break down of family structures) in directing the epidemiology of schizophrenia incidence is also beginning to be recognised (Burns, 2012). This lends further support the urgent need to address this illness in Africa.

The experience of schizophrenia and psychosocial disability

A person with schizophrenia may experience a variety of impairments, including upsetting hallucinations and delusions (positive symptoms), reduced ability to concentrate, a lack of energy and motivation, social withdrawal and reduced ability to plan for the future and set goals (negative symptoms) (Craig, 2006; Starkey & Flannery, 1997). These symptoms lead to lowered functioning, reducing the person's ability to function in their social environment including family, work, and community interactions. Together these effects create a growing sense of being out of control and failing to exercise mastery over the environment (Starkey & Flannery, 1997). This can affect a number of areas: performing tasks related to personal health and hygiene; maintaining a household; functioning in a work environment, retaining financial independence or avoiding debt; taking advantage of educational and vocational opportunities; and forming and keeping significant personal relationships (Craig, 2006). People with schizophrenia may also have subtle abnormalities in their attention and cognitive function, as well as more overt behavioural issues that make it difficult for them to fulfil certain social roles (King, 2007). These effects in turn negatively impact on self-image and self-esteem (Starkey & Flannery, 1997).

Psychosocial disability is compounded by the vicious stigma against people with severe mental illness, particularly in LMIC. This remains a failure of global morality and humanity (Kleinman, 2009; Sartorius, 2007). In many parts of the world people with severe mental illness are at best ignored, excluded from meaningful aspects of ordinary life, and at worst subjected to major violations of their human rights (Kleinman, 2009; Patel et al., 2007b). Families and communities (including health workers) exclude those with psychosocial disability due to fear, lack of understanding of their illness and discrimination. People with schizophrenia can feel intensely isolated (Herman et al., 2005). Each stigmatising experience batters their self-esteem

and belief in their chances of success in the future as well as their sense of belonging to a supportive community (Corring, 2002; Kahng & Mowbray, 2005; Onken et al., 2007; Sartorius, 2007). People often respond to mistreatment by further isolating themselves as a protective mechanism which leads to loss of social skills (Chovil, 2005; Starkey & Flannery, 1997).

Beyond these individual level effects, schizophrenia exerts a substantial burden on caregivers. In LMIC the lack of community services means that people with this illness usually live with family, if they are not hospitalised or otherwise isolated from their community (e.g., residing with a traditional healer). The care needs of a person with schizophrenia can be demanding and can reduce quality of life and functioning of the primary caregiver. They can also significantly increase financial strain and stress (e.g., because a caregiver is unable to retain employment) (Caqueo-Urizar & Gutiérrez-Maldonado, 2009). The burden of care can be particularly high for women, notably mothers who may be the primary and sole caregivers for a child who develops the illness (Caqueo-Urizar & Gutiérrez-Maldonado, 2006). Family members may also experience fear of stigma and mistreatment due to having a relative with mental illness (Balaji et al., 2012; Patel et al., 2007b).

Poverty and mental illness are intricately linked in LMIC in a vicious cycle (Lund et al., 2011) and schizophrenia disproportionately affects those with low socioeconomic status (SES) (e.g., low income/education levels). There is a long history of research linking lower social class and living in deprived areas to this disorder in HIC (Saraceno et al., 2005). This social causation pathway (lower social status conducive to development of illness) (Kohn et al., 1998; Muntaner et al., 2004; Saraceno et al., 2005) is then exacerbated by social drift (movement down the socioeconomic hierarchy/failure to improve socioeconomic status due to illness) which is

particularly detrimental in the case of schizophrenia (Dohrenwend & Dohrenwend, 1969; Dohrenwend et al., 1992; Muntaner et al., 2004). A recent systematic review also showed an association between higher schizophrenia incidence and higher levels of income inequality across 26 countries (Burns et al., 2014). Low SES may also further disadvantage those with severe mental illness by impairing their ability to access treatment and support (Plagerson, 2015). Approximately two thirds of people with schizophrenia in LMIC have no access to any form of specialized mental health care. These levels are higher for those living in poverty or otherwise excluded from society (e.g., migrants) (Lora et al., 2012). Stigma, social exclusion and lack of appropriate treatment and support can also effectively exclude those with schizophrenia and their families from poverty-reduction programmes where they exist (Plagerson, 2015). It is not surprising then that people with severe mental illness and their families may be some of the most deprived in any society, particularly in LMICs without social welfare supports (Jenkins et al., 2011b).

The Recovery Model

Long-term support for people with schizophrenia is focused on “recovery” as opposed to cure. The recovery model that has developed in HIC settings has been termed an individual journey incorporating reduction in psychotic and cognitive symptoms and improved psychosocial functioning, quality of life, and self-agency (Lieberman et al., 2008; Van Dyke, 2013). It is seen both as an *outcome*, whereby people learn to cope with the psychosocial disability in their lives (which may continue to be present to varying degrees) and as a *process* of bringing hope, empowerment, goal orientation and a sense of fulfilment (Anthony, 2003; Craig, 2006; Deegan, 1996; Onken et al., 2007). Recovery in HIC is grounded on (amongst other factors) forming or rebuilding meaningful relationships, fostering empowerment and improving access to

employment. It is characterised by collaborative treatment approaches and peer support (Warner, 2009). People recover first from the illness itself and the symptoms and disability it causes through a process of knowing, accepting and exercising mastery over the illness (Jacobson, 2001; Onken et al., 2007) and reducing internalized stigma (Warner, 2009). Secondly they recover from the discrimination and “othering” of wider society through finding meaningful roles in their community (Onken et al., 2007). To enable recovery a person’s environment needs to provide opportunities and resources for them to make meaningful choices (e.g., on work, education, personal relationships) (Onken et al., 2007).

If seen as an individual journey, recovery is of necessity linked to the sociocultural environment in which an individual finds him/herself (Van Dyke, 2013). There are important differences between Western sociocultural contexts and LMIC contexts (e.g., use of traditional healers, greater involvement of families in providing care, higher levels of gender inequality) (Higgins et al., 2007). These may make recovery “look” different in these contexts. A key limitation to the relevance of the “Western” recovery model is that it is rooted in well-resourced health systems in HICs with economic environments able to provide for people’s material needs. In these settings much emphasis is placed on the dominant Western notion of the “power of the individual...to earn their way back into the mainstream of society ” (Onken et al., 2007), p 18, particularly in terms of regaining employment. This can narrow the focus of recovery, placing all responsibility on the individual. Western recovery models relying heavily on individual empowerment have also been critiqued for creating significant stress in trying to empower people to become “esteemed self-made citizens” (Myers, 2010), p. 500. In non-Western contexts more cooperative approaches may be appropriate (e.g., the family and community are involved in creating meaningful roles and a supportive environment) (Onken et al., 2007). It follows that the recovery journey may “look” different for individuals in LMIC since they may

not have the options of supported housing, employment and welfare payments. Recovery in LMIC is also therefore intricately linked with poverty alleviation, development, and working for social inclusion (Petersen et al., 2011; Plagerson, 2015). There are however, likely to be many aspects of the recovery journey relevant both to HIC and LMIC contexts and key learnings for LMIC from interventions aiming to promote recovery in HIC.

The evolution of schizophrenia care: psychosocial rehabilitation

Historically, long-term care for people with schizophrenia, as with other severe mental disorders, was through institutionalisation in “asylums” and later, hospitalisation in specialist psychiatric hospitals. Movements promoting human rights and advocating for less restrictive care have led to deinstitutionalisation in many countries. This human rights approach for treatment and care developed from the movement in Trieste, Italy for deinstitutionalisation of patients from “mental hospitals”. This was spearheaded by individuals including Benadetto Saraceno and Michele Tansella in the 1970s and 1980s (Jenkins et al., 2011c). The current understanding of comprehensive care for those with schizophrenia therefore both addresses the illness and embraces a human rights approach. This encompasses provision of antipsychotic medication and the least restrictive form of long-term care, ideally psychosocial rehabilitation (PSR) enabling community living and promoting social inclusion. The drive for community living promoted the development of the recovery model and specific approaches to PSR [e.g., the Boston Model (Anthony, 2002)]. Interventions within the PSR approach aim to promote recovery by reducing symptoms (pharmacological and psychological treatment), reducing stress (which aggravates symptoms), building protective factors (e.g., coping skills) and promoting social inclusion (e.g., through employment) (Craig, 2006). Many HIC have embraced deinstitutionalisation and there is a robust evidence base for specific psychosocial

interventions promoting recovery in HIC. The Schizophrenia Patient Outcomes Research Team (PORT) in 2010 recommended eight psychosocial treatments (assertive community treatment (ACT), supported employment, cognitive behavioural therapy, family-based services, token economy, skills training, psychosocial interventions for alcohol and substance use disorders, and psychosocial interventions for weight management) (Dixon et al., 2010). Recent Cochrane reviews also supported the effectiveness of psychoeducation for patients (Xia et al., 2011); family psychosocial interventions (Pharoah et al., 2010); and music therapy (Gold et al., 2005) on a variety of non-clinical outcomes (e.g., social functioning). Another recent Cochrane review showed no significant positive effects of Life Skills Training compared with standard care or being part of support groups. However gaining social life skills is an important part of regaining self-esteem and social acceptance in the recovery process and the authors of this review acknowledge that more robust studies may be needed to be able to evaluate this effect (Tungpunkom et al., 2012). Notably however, even in HIC, few of these interventions have been implemented at scale (Patel, 2015).

The variety of medical and psychosocial needs of people living with schizophrenia also necessitates a strong service delivery structure. The model of “Assertive Community Treatment” (ACT) characterised by biomedical treatment and psychosocial support delivered by coordinated multidisciplinary teams (Bond et al., 2001) has evolved to the current practice of “Intensive Case Management” (ICM) further characterised by small caseloads (Dieterich et al., 2010; Fu Keung Wong, 2013), and similarly involving multidisciplinary specialist community-based teams (comprising psychiatrists, nurses, social workers, psychologists, occupational therapists and others). These teams work together closely with service users, families and local community services (e.g., social welfare and housing sectors) (Alem et al., 2008).

Psychosocial rehabilitation in the LMIC context

The capacity to deliver ACT or ICM for PSR in LMIC is clearly constrained by resource limitations particularly for implementation at the scale required to meet population needs. For more than a decade there have been calls for resources previously allocated to psychiatric hospital beds to follow patients into the community for provision of community-based services (Thornicroft et al., 2010; WHO, 2003). This is crucial to avoid the “revolving door phenomenon” (repeated discharge into the community and rehospitalisation following relapse due to inadequate supportive services). Particularly, hospital services should only be downscaled once community services are available to support discharged patients and the process of deinstitutionalisation should not be seen as a chance to cut mental health budgets (Petersen et al., 2011). The redirection of resources requires complex planning as well as technical support from countries that have successfully implemented this service delivery change (Saraceno et al., 2007). Consequently reorientation of services to wide-scale community-based services remains a challenge for many LMIC (Alem et al., 2008; Hanlon et al., 2010; Thornicroft et al., 2010). The community-based mental health resources that are available tend to be concentrated in urban areas and near cities rather than according to population needs (Saraceno et al., 2007). Due to this resource crisis, replication of the HIC models for PSR is unlikely now, and into the future. Feasible models may need to rely on task-sharing approaches. Experience of researchers and NGOs to date indicates that the most appropriate service model will be a collaborative model, drawing on patients/service users, family members/caregivers and non-specialist workers at community level, and providing access to a psychiatrist (Patel, 2015). Practical approaches to delivery of psychosocial interventions in low resource contexts include the understanding of outcomes desired by patients themselves and the subsequent use of low intensity, non-specialist delivered

psychosocial supports (e.g., psychoeducation, adherence support, self-help groups, social case work) (Patel, 2015).

Despite resource challenges the focus for PSR in LMIC should remain on reduction of psychosocial disability enabling people to reach their optimal level of functioning in their own community (Argadona, 1996). Specific goals include helping people gain skills and access resources that improve their capacity to live fulfilling lives, and addressing discrimination and poverty (Anthony, 2009). In terms of specific interventions for schizophrenia in LMIC, PLoS Medicine in 2009 published a series of articles on packages of care for mental disorders, including schizophrenia, appropriate for LMIC. These are grounded on a stepped-care model for feasible delivery in LMIC settings by non-specialists in a task-sharing approach (Mari et al., 2009). Community-based rehabilitation, psychoeducation and support for families delivered by non-specialists are recommended (Mari et al., 2009; Patel et al., 2007b). WHO also developed the mhGAP intervention guide (WHO, 2010) for addressing mental disorders in primary care. Guidelines for psychosis include provision of antipsychotic medication and encouraging primary health practitioners to facilitate rehabilitation in the community. WHO also promotes Community Based Rehabilitation (CBR) as a basis for poverty reduction, equalisation of opportunities and social inclusion (WHO, 2004). It follows that effective approaches for PSR in these contexts are vital not just to address the needs of service users, but as a vital aspect of breaking the cycle of poverty and severe mental illness (Flisher et al., 2007).

A recent Cochrane review of CBR approaches included five studies of CBR for schizophrenia and highlighted the lack of robust evidence specifically for this mental disorder in LMIC (Iemmi et al., 2015). Another Cochrane review found too few studies to draw conclusions on

the benefits of non-specialist delivered interventions for schizophrenia in LMIC (van Ginneken et al., 2013). Similarly, a further systematic review of randomized controlled trials (RCTs) for psychosocial interventions for schizophrenia in LMIC, looking specifically at effects on social functioning, suggested evidence for positive effects on social functioning but highlighted a lack of evidence from high quality trials (De Silva et al., 2013). Studies not included in that review (e.g., non-randomized studies and those with outcomes other than social functioning) do suggest effectiveness of task-shared psychosocial interventions in LMIC. These include collaborative community care in India (Chatterjee et al., 2014; Chatterjee et al., 2003; Chatterjee et al., 2009), family interventions in Iran (Koolae & Etemadi, 2010), social skills training in Mexico (Valencia et al., 2007), community re-entry training in China (Xiang et al., 2007) and community care in Chile (Alvarado et al., 2012). Most evidence that is mounting is for psychoeducation interventions (not only task-shared) for service users and family and caregivers from a variety of LMIC, for example, China (Xiang et al., 1994; Zhang et al., 1998), the Czech republic (Motlova et al., 2004), Nigeria (Agara & Onibi, 2007), Chile (Gutierrez-Maldonado et al., 2009), Iran (Fallahi Khoshknab et al., 2014; Karamlou et al., 2009), Jordan (Hasan et al., 2014), Malaysia (Paranthaman et al., 2010) and India (Kulhara et al., 2009).

The “older”, less expensive antipsychotic medication combined with psychosocial interventions delivered in a community-based service model have been shown to be cost-effective for treating schizophrenia in LMIC (Chisholm et al., 2008; Chisholm & WHO, 2005). Notably, adjunct psychosocial interventions are more cost-effective than pharmacotherapy alone due to the moderate additional costs but important health gains from the psychosocial interventions (Chisholm & WHO, 2005; WHO, 2006).

There is therefore a strong basis for making the case for provision of community-based services for schizophrenia, but progress on the ground remains inconsistent and peer-reviewed studies from LMIC are still lacking. Part of the reason for both a lack of a robust evidence base and for Government-led scale-up for PSR in LMIC is that these services have largely been provided by the NGO sector (Petersen et al., 2011; Rangaswamy & Sujit, 2012). This is often with little coordination between individual organisations, and between the NGO sector and relevant Government departments. Notable NGOs in this area include Schizophrenia Research Foundation (SCARF) and the Richmond Fellowship in India, and BasicNeeds which works in both in Africa and Asia. BasicNeeds has developed the “Model for Mental Health and Development” which addresses the cross-cutting health, social, and economic concerns faced by people with mental illness by enabling people to access livelihood development strategies and social support (BasicNeeds, 2008b; BasicNeeds, 2009). BasicNeeds programmes have had effects on economic and social outcomes, including increasing the numbers of people earning an income, giving them a sense of inclusion and identity; reducing the burden on caregivers; decreasing levels of disability in social functioning; and improving self-care (BasicNeeds, 2008a; Raja & Kippen, 2008; Raja & Kippen, 2008).

NGOs do however face a variety of challenges in providing sustainable services due to provision of funding for specified and limited duration. Their services are often not fully integrated with those provided by the Health and Welfare sector to ensure continuity of care (Rangaswamy & Sujit, 2012). A 2010 World Psychiatric Association (WPA) report highlighted that globally a significant obstacle to provision of community-based mental health care (including PSR) is that non-sustainable programmes are implemented by international NGOs and there is a lack of multisectoral collaboration (Thornicroft et al., 2010). Further challenges include lack of connection between mental health services and other relevant services in the

health system, small numbers of trained workers (due to the length and intensity that providing a comprehensive intervention may take) and reluctance of practitioners to focus attention to patients living in the community as opposed to long-stay hospital patients who are more accessible (Rangaswamy & Sujit, 2012). Within this set up, patients run the risk of being referred from one service to another within the health system and/or in the community with little continuity of care (Saraceno & Dua, 2009). Addressing psychosocial disability within a human rights framework suggests a social inclusion approach, in which all relevant organisations and sectors need to be strengthened. Integration and communication need to be improved to enable assessment of disabling factors in the environment, addressing these factors (Petersen et al., 2011) and provision of coordinated services (Petersen, 2010).

Psychosocial rehabilitation – the South African context

Unlike many other African countries, some of which lack Mental Health Policies, or have limited implementation of existing policies (Omar et al., 2010), there has been some commitment to addressing mental health in South Africa since the 1990s. A chapter on mental health was included in the influential “White paper for the transformation of the health system in South Africa” (1997). The Mental Health Care Act 2002 promulgated in 2004 is supportive of human rights of people with mental illness and oriented to the provision of community care (Draper et al., 2009). The 1997 Mental Health Policy and Guidelines were seen to lack clear objectives and the required focus on intersectoral collaboration to address the link between poverty and poor mental health. Lack of capacity to implement policy (Omar et al., 2010) then led to limited and inconsistent implementation of the policy across the provinces (Draper et al., 2009; Marais & Petersen, 2015).

The South African Department of Health (DOH) has since made important progress towards the provision of comprehensive mental health services, particularly through the development of the National Mental Health Policy Framework and Strategic Plan 2013-2020 (DOH, 2013). This includes provision for community residential care and task-shared community-based rehabilitation programmes in all provinces. Implementation of new mental health policy comes in the wider context of health system strengthening in South Africa in which DOH is embracing the Integrated Chronic Disease Management (ICDM) model (Mahomed et al., 2014). ICDM is a reorientation of the entire system to holistically address the increasing burden of chronic diseases by coordinating services for affected individuals “over an extended time period and across disciplines” (Mahomed et al., 2014), p1724. This includes empowering patients to take control of their own health with an increased focus on health promotion and assisted self-management in the community (Mahomed et al., 2014). The model harnesses learnings and approaches from the South African HIV response. Cadres currently allocated for HIV services (adherence counsellors, home based carers) will be reoriented to focus on all non-communicable diseases, for example, through tracing patients who miss appointments and carrying out adherence counselling (Mahomed et al., 2014).

Although there have been no nationally representative epidemiological studies, annual schizophrenia prevalence has been estimated at 1% in one South African province (Western Cape) (Kleintjes et al., 2006). Psychotropic medications are accessible for inpatients (Lund et al., 2010), however there is also evidence that psychosocial needs of inpatients are not met in some contexts (Joska & Flisher, 2007). Psychotropic medication is meant to be regularly available at primary health clinics country wide, but this is not the case in all areas, contributing to lowered adherence, relapse and the revolving door phenomenon (Petersen & Lund, 2011). South Africa has made rapid progress in down-sizing of specialist psychiatric hospitals (DOH,

2013) that has not been accompanied by the ring-fencing of money saved for direction to community-based services recommended in South Africa (Petersen & Lund, 2011), and internationally (Thorncroft et al., 2010). There has also been unsatisfactory intervention research for community-based services, including PSR, as well as inadequate beds in general hospitals, and limited community-based residential care (Petersen & Lund, 2011). A task-sharing approach has been recommended to address the gap in community services in view of continuing resource constraints in the sector. However to date there are few intervention studies to provide evidence for this approach to PSR in South Africa (Petersen & Lund, 2011). Studies in more well-resourced urban settings have shown the potential for a modified model of ACT (nurse-/social worker-led) (Botha et al., 2014; Botha et al., 2010) and group-based family therapy (nurse-led) (Asmal et al., 2013). However these may not be feasible in all parts of the country due to resource constraints in certain geographical areas. All community mental health services in South Africa have generally been poorly resourced and provided inequitably across the country, with human resources greatly concentrated in hospital settings (Lund & Flisher, 2003). Services for psychosocial and pharmacological treatment need to be linked both at the level of the sectors/agencies responsible for services (e.g., health, social services) and at the level of practitioners (e.g., social workers and health workers) (Lieberman, 2008). A more structured approach for intersectoral action is needed in South Africa at provincial and district level (Skeen et al., 2010).

Similar to other LMIC, current service provision for PSR in South Africa continues to be mainly through NGOs (Petersen et al., 2011) (e.g., South African Federation for Mental Health and its provincial Mental Health Societies). These NGOs are partially funded through subsidies by the Department of Social Development (DOSD) to provide this service, under the Policy on Disability which identifies the DOSD as having primary responsibility for provision of

community-based services, promoting social integration and rehabilitation for people with mental disabilities (DOSD, Undated). Notably DOH is not currently funding these NGOs. South Africa's National Rehabilitation Policy (DOH, 2000) recognises the importance of working closely with NGOs and community-based organisations (CBOs) who are ideally placed to help provide rehabilitation services (DOH, 2000). However, lack of resources within the health system and in the NGO sector, as well as a lack of collaboration between the various government sectors who share responsibility for different aspects of PSR (e.g., Health, Social Development, Housing, Labour) means programmes for PSR are lacking in many areas. A 2011 review found more than 10 articles outlining inadequacies in provision of community-based PSR, particularly in rural areas (Petersen & Lund, 2011). Evidence for feasible approaches for community-based PSR are therefore urgently needed and it is to this research gap that this PhD contributes.

Theoretical framework guiding the study

The theoretical framework guiding the work of this study is in two parts: (i) theory guiding the understanding of the intervention context and the content of the intervention and (ii) theoretical basis for the evaluative component of the study. Both these areas are elaborated below.

Theory guiding understanding of context and intervention development

The theory drawn on for this part of the study is based on two premises regarding the experience of psychosocial disability for people with schizophrenia in South Africa. Firstly, that the experience of psychosocial disability is both dependent on individual impairments, and socially mediated by family, community members and wider society. Secondly, that while recovery is

an individual journey, an individual's environment, particularly access to meaningful opportunities and choices, exerts a strong effect on the individual's ability to recover.

With this understanding, the historical individual/medical understanding of disability is of limited value, but the social model of disability includes the recognition that disability does not rest within the individual alone, and that societies can be disabling to those who live in them (Barnes & Mercer, 2004; Oliver, 2004). This construction challenges the causal link between an impairment and disability, focusing instead on how society restricts the ability of those with the impairment (e.g., people with schizophrenia) to take part in economic and social activities that are important parts of life (i.e., social inclusion) (Oliver, 2004). Disability is seen as “the outcome of an oppressive relationship between people with . . . impairments and the rest of society” (Finkelstein, 1980), p. 47 cited in Barnes, 2010). Similar to the vicious cycle of poverty and mental ill health discussed previously, the social model acknowledges that there is an ongoing link between poverty, disability and social exclusion founded on the inability of those with disability to gain formal income or employment, food, housing, transport, and education (Barnes & Mercer, 2010).

A principle critique however of this social model is that as much as disability does not lie solely within the person, neither is it simply a result of environmental factors. Rather it can be understood as the interaction between impairments and characteristics of the environment in which a person lives (Onken et al., 2007). WHO's International Classification of Functioning, Disability and Health (ICF)¹ (the biopsychosocial model) acknowledges this interaction, showing that mental illness affects multiple “domains” of an individual's life (body, mind, and

¹ <http://www.who.int/classifications/icf/en/>

social interaction/participation) and that these domains are linked (King, 2007). This enables a delineation between impairments (within the individual) and disabling barriers (within the environment) in conceptualising interventions, and highlights the need to target both areas (Barnes & Mercer, 2004). It follows that addressing psychosocial disability in the context of this PhD is dependent not only on providing support for individuals (Barnes & Mercer, 2004) (e.g., through improving insight into their illness), but also on working to promote social inclusion (e.g., by improving relationships or providing access to income generation). The biopsychosocial model also fits well with the widely established stress-vulnerability hypothesis of schizophrenia causation. This suggests that it is the interaction between individual (e.g., genetic, biological) and environmental factors (e.g., emotional distress, life events) that leads to the development of the illness and contributes to relapse (Ingram & Luxton, 2005; Nuechterlein & Dawson, 1984; Walder et al., 2014).

In support of the second theoretical premise of this work regarding meaningful opportunities and choices, the primary theory of relevance is the influential work of the economist Amartya Sen. This theory describes the capabilities approach to disability, which is in many respects complementary to the social model (Burchardt, 2004). Under this approach, Sen notes that any person's ability to maximise their utility is dependent on opportunities and useful options available to them. Inequality and disadvantage in this regard are mediated by social, economic and environmental constraints (Mitra, 2006; Sen, 1999). A person's "capabilities" are determined by the opportunities available to them, and their ability and freedom to choose from these opportunities and thereby have meaningful participation in society (Hopper, 2007; Mitra, 2006). In this view, disability is seen as a reduction in the capability of an individual to take up practical opportunities to do things they value (Mitra, 2006; Sen, 1993). People with severe mental illness, and most especially those living in poverty, have limitations on their ability to

contribute fully in society, and may have little education and limited opportunities for employment and income generation (Lund, 2012). This relates to their lack of what Sen has termed “substantive freedoms” which are instrumental to the development of capabilities. Consequently the lack of these freedoms leads to capability deprivation (Sen, 1999). This approach also recognises social exclusion (e.g., by discrimination, exclusion from social/cultural activities) as a crucial element of capability deprivation (Sen, 1999; Sen, 2000).

Further relating this approach directly to the experience of those with severe mental illness such as schizophrenia, a person’s freedom of choice and agency to recover is restrained when they lack the psychological (e.g., resilience), social (e.g., family, friendships), material (e.g., housing) and financial resources (substantive freedoms) to achieve their goals and live a meaningful life. Income support for people with disabilities even in HIC with well-developed social support systems has been critiqued as inadequate due to higher costs associated with living with a particular disability. For example a household with a person with a chronic illness is estimated to need 40% greater income to reach the standard of living of an unaffected household (Mitra, 2006). In low resource LMIC contexts (and particularly in the poorest communities) challenges to these substantive freedoms based on poverty may thwart even the strongest individuals’ efforts towards recovery. An ideal to pursue would be for people with psychosocial disability to “participate fully in society on an equal basis” (Burchardt, 2004) p. 740. In this context, because of the need to fulfil basic needs to enable substantive freedoms, income generating activities could be seen as the main priority for intervention. This could lead to little emphasis on “recovery” in the true sense of the word with the “repeated making of baskets or rugs with little incentive or psychological and social measures to improve quality of life” (Deva, 2006), p. 2. Sen, however, views poverty not simply as lack of income, but as “capability inadequacy” (Sen, 1999), while acknowledging that income is an important

instrumental factor for generating capabilities and that assessing the economic context is part of assessing disability (Mitra, 2006). So addressing this poverty/capability inadequacy would encompass more than simply increasing income. Although income levels of people with schizophrenia in South Africa are supported by state disability grants (maximum of 1410Rand/100 USD per month) a key concept of capability theory is that the relation between low income (as a challenge to substantive freedom) and low capability, is different for different individuals. A person with psychosocial disability caused by schizophrenia may experience “adversity in converting income into functionings” (Sen, 1999), p. 88 or into a standard of living that they value. Thus the disadvantage or capability deprivation of people with disabilities in deprived settings is deepened by the cumulative effect of low income with low ability to convert income to capabilities (Mitra, 2006; Sen, 1999). For example a person living in a deep rural area may spend a significant portion of their income from a disability grant to travel to a clinic or hospital to collect medication or see a health professional, leaving little for the achievement of other aspects of value in life (or even basic needs). The capabilities approach goes beyond seeing income as a good indicator of quality of life (Burchardt, 2004) and underscores the need to address multiple deprivations which affect people with schizophrenia significantly (Lund et al., 2010).

In view of these considerations, PSR in the LMIC context needs to increase substantive freedom of people with schizophrenia through creating a system of support that begins to provide for crucial material, social and psychological needs. In South Africa this will mean building on the fact that although poverty makes the life circumstances of people with psychosocial disability extremely challenging, they can access disability grants, and they can and do mobilise coping strategies by drawing on locally relevant ways of knowing and “being-in-the-world” (Duncan, 2009). An intervention recognizing and encouraging the capabilities of

people with schizophrenia is indicated, focusing on what people are capable of achieving in their lives, dependent on (i) their individual characteristics (e.g., level of impairment); (ii) the resources available to them (e.g., income from grant); and (iii) the environment (physical, social, political, economic) (Mitra, 2006; Sen, 2004). From this standpoint services, resources, and support are important due to what they enable a person to achieve in terms of valued roles and functions in their lives (Hopper, 2007; Sen, 1993).

In terms of intervention design a self-help/support group approach is indicated by WHO CBR guidelines and supported by social support theories (Bartholomew, 2001) and experience from other African countries (e.g., Cohen, Raja et al., 2012). Self-help/support groups can provide members with emotional, instrumental, material, informational and particularly appraisal support which helps in promoting positive self-worth and identity (Petersen & Govender, 2010). These groups provide members with the opportunity to build relationships that are socially supportive and built on trust, empathy, and a history of similar experiences (Heaney & Israel, 1997). Membership of such a group increases the human and social resources that people can rely on in their social environment (Petersen & Govender, 2010). Building social support in these ways also links with social capital theory as defined by Carpiano whereby building emotional, instrumental and other supports enables individuals to more effectively face life challenges (Carpiano, 2006). This choice of an intervention strategy is also beneficial in light of the suggestion that people with highly stigmatized disorders (such as schizophrenia) may gain significant benefits from social support groups (Petersen & Govender, 2010). It is important to acknowledge that bringing together patients with a highly stigmatised disorder may also be disadvantageous in further isolating these patients from their community at large. There is currently a dearth of evidence not only on effectiveness but also on acceptability and

feasibility of contextually relevant PSR interventions for people with schizophrenia in South Africa.

Theoretical basis for the evaluative component of the study

Since 2000 the UK Medical Research Council (MRC) guidance for complex interventions has brought structure to the process of designing and evaluating interventions in the public health and social policy sphere (Campbell et al., 2000; Craig et al., 2008). Interventions in mental health in low resource contexts particularly may be complex because of the multiple societal and individual factors influencing both the development and course of mental disorder and the context for implementation of an intervention.

Based on the wide use of the MRC guidance and the experience and feedback this generated, updated guidance was developed in 2008. This promotes increased attention to piloting and intervention development work and recognition of the importance of tailoring of complex interventions to specific contexts (Craig et al., 2008). The current guidance outlines best practice including (i) using the best available existing evidence in the area; (ii) basing the intervention on appropriate theory; (iii) using a phased approach to evaluation beginning with pilot studies (which may be multiple) to clarify aspects of the design and implementation; and (iv) a preliminary and then definitive evaluation (which may or may not be a RCT) (Craig et al., 2008). A key provision of this guidance is that these steps are not linear, they may be cyclical with feedback in different directions in an iterative process of refining and evaluating the intervention (Steps 1-3, Figure 1).

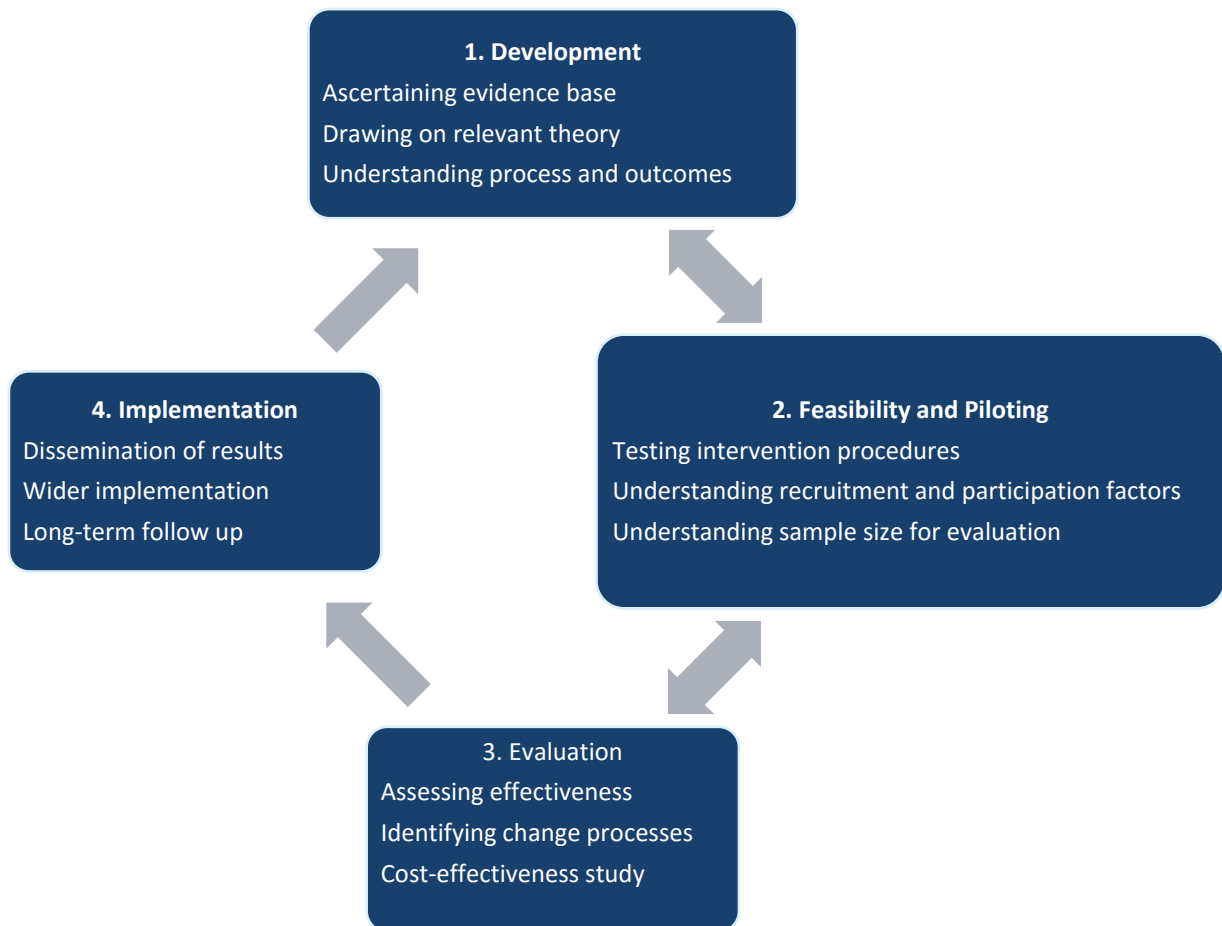


Figure 1. Key elements in the MRC Framework for design and evaluation of complex interventions Adapted From (Craig et al., 2008)

Within this framework, the work of this PhD falls under Steps 1 and 2. This represents significant work in the development, design and piloting of the intervention. These steps are key before consideration of experimental methods to contribute to a definitive evaluation of effectiveness of the intervention.

Step 1 Intervention development

Under Step 1, the work in this PhD draws on what is known about similar interventions – in this case through the systematic review conducted (see Objective 1). The use of relevant theory

to guide the intervention development and understand possible mechanisms of action of the intervention is also described in the previous section on the theoretical basis for the intervention development. Supplementation of theoretical knowledge by new primary research is also indicated in the MRC guidance (Craig et al., 2008) and was conducted in the formative study informing the PSR intervention (see Objective 2 in Chapter 2).

Step 2 Feasibility and Piloting

Assessing feasibility refers to piloting the intervention before a larger scale evaluation, and conducting a process evaluation to understand procedural factors. This is a core contribution of the work of this PhD and fulfils two important functions. Firstly, it allows for an understanding of factors that will influence effectiveness of the intervention including acceptability, participation and intervention delivery (Craig et al., 2008). Secondly, it allows for the identification of “key uncertainties” that affect implementation. The MRC guidance acknowledges that there will always be a variety of constraints that impact on the implementation of an intervention and thus its effectiveness (Craig et al., 2008). Understanding and working within these constraints to maximise the effectiveness of the intervention is an important function of a pilot study. In terms of wider implementation, it is crucial that both process and outcome evaluations are well reported with a distinct description of the intervention to facilitate replication and further evaluation. The work in this PhD addresses this requirement (see Objectives 3 and 4).

Overview of the PhD Study and The Programme for Improving Mental Health Care (PRIME)

Introduction to PRIME

This PhD study was part of The Programme for Improving Mental Health Care (PRIME), a research consortium of partnering research institutions and Ministries of Health in five countries in Asia and Africa (Ethiopia, India, Nepal, South Africa and Uganda), with other partners in the UK and the World Health Organization (WHO) (Lund et al., 2012). PRIME aims to generate evidence for implementation and scale up in low-resource settings of programmes for priority mental disorders (depression, alcohol abuse, schizophrenia in South Africa). PRIME researchers in South Africa have collaborated with the South African Department of Health in Dr Kenneth Kaunda district of the North West (NW) Province to develop a Mental Health Care Plan for the district. The intervention described in this thesis is a component of this plan (Petersen et al., 2015).

PhD Aim and Objectives

The aim of this research project was to develop and assess the feasibility and acceptability of a context-specific PSR intervention for people living with schizophrenia to be implemented by non-specialist workers in South Africa. The thesis thus contributes to the developing field of task-shared mental health interventions in South Africa and to the broader field of intervention development for psychosocial interventions for schizophrenia in LMIC. The thesis describes the research project process of in-depth formative work, corresponding intervention and materials development, piloting and formative evaluation, in line with the initial steps of the

MRC Framework for complex interventions (Craig et al., 2008). Specifically the thesis covers five objectives, with each objective linked to a publication or output:

1. Objective 1. To undertake a systematic review of factors affecting acceptability and feasibility of psychosocial interventions for schizophrenia in LMIC to inform development of the intervention.
2. Objective 2. To conduct formative qualitative research with service users with schizophrenia and their caregivers to understand perceptions of the illness and contextual factors to inform the intervention.
3. Objective 3. To develop a contextually appropriate, manual-based PSR intervention nested within the PRIME collaborative care model for schizophrenia.
4. Objective 4. To conduct a pilot study and formative evaluation to assess factors affecting acceptability and feasibility for potential refinement and wider implementation of the intervention.
5. Objective 5. To undertake a qualitative investigation into challenges and ways forward for addressing lack of intersectoral collaboration as a key structural barrier to the scale-up of PSR in South Africa.

The papers in the thesis and the intervention manuals consecutively present the evidence and practice integrated in the PhD research project. Together these outputs systematically document the process of developing, piloting, and assessing the feasibility and acceptability of the tailored approach to PSR in this South African context. The Training Manual and Facilitator Guide for the intervention (developed by the candidate) in particular represent key outputs of the intervention development process and a significant part of the work of the PhD.

Objective 1: Paper 1: Systematic review of feasibility and acceptability of psychosocial interventions for schizophrenia in low and middle income countries

Authors: Carrie Brooke-Sumner, Inge Petersen, Laura Asher, Sumaya Mall, Catherine O. Egbe, Crick Lund (published, BMC Psychiatry)

This paper aimed to systematically review evidence of the feasibility and acceptability of community-based psychosocial interventions for schizophrenia in LMIC (not limited to task-shared interventions). The questions of feasibility and acceptability of these interventions in LMIC contexts are relevant given continuing low levels of resources for mental health in LMIC, and the fact that many psychosocial interventions for schizophrenia have been initially developed in HIC contexts. Outputs of the review are recommendations for improving acceptability and feasibility, which were incorporated into the development of the intervention in this study.

Author contributions: CBS led development of the search protocol, reviewed initial abstract database, conducted quality assessment and qualitative synthesis, compiled first through final drafts. CL advised on search protocol, inclusion and exclusion and data analysis process. IP contributed to development of search protocol, advised on analysis. LA contributed to development of search protocol, developed search strategy, conducted database searches. SM reviewed initial abstract database. COE reviewed included and excluded articles and quality checked data. All authors approved drafts and final manuscript.

This review highlighted that evidence on acceptability and feasibility for community-based psychosocial interventions for schizophrenia in LMIC is currently limited, particularly so for feasibility data. Operationalisation of feasibility and acceptability as constructs in future

research is needed. Recommendations from Paper 1 were included in development of the Training Manual for intervention workers (PSR group Facilitators) and the Facilitator Guide for implementation (see Objective 3). The other aspect of formative work regarding understanding the experiences of service users with schizophrenia and their caregivers is described in Paper 2.

Objective 2: Paper 2: Perceptions of psychosocial disability among service users and caregivers in South Africa

Authors: Carrie Brooke-Sumner, Crick Lund, Inge Petersen (published, African Journal of Disability)

In line with the theoretical basis of the study in viewing the experience of illness and psychosocial disability within the biopsychosocial model of illness, and in consideration of the relevance of explanatory models and lived experience to the development of context-specific interventions, this paper aimed to report experiences and perceptions of illness, disability and recovery amongst service users with schizophrenia and their caregivers. This was intended to inform the cultural and contextual appropriateness of the intervention developed through the PhD study.

Author contributions: CBS conceptualised the study, contributed to the interview schedules, oversaw data collection, conducted analysis, prepared first through final drafts. IP contributed to conceptualisation and interview schedules, managed the research process. CL aided in conceptualisation and analysis. All authors approved drafts and final manuscript.

This paper identified experiences and needs of service users with schizophrenia and their caregivers from within the district of the planned pilot intervention, providing an in-depth understanding of the context and contributing to the understanding of the experience of living with severe mental illness in South Africa. The use of this contextual information for the development of the intervention is described under Objective 3.

Objective 3: The Collaborative Care Model for Schizophrenia and intervention materials for the PSR intervention – (Facilitator Training Manual and Facilitator Guide)

The diagram on the following page illustrates the collaborative care model for schizophrenia as developed within the PRIME district Mental Health Care Plan. This plan was developed in a collaborative process involving a wide variety of stakeholders from the district involved in the provision of mental health services. Collaborative care models for depression, alcohol abuse and schizophrenia (priority conditions identified) were generated. Development of the plan was guided by the Theory of Change process which is a tool for addressing complex health/social issues in the development context (Breuer et al., 2014). The Theory of Change process allows planners to look at intervention components and prerequisites required to create change on desired outcomes (Breuer et al., 2014) (in this case, improvements in care for depression, alcohol abuse and schizophrenia). Stakeholder workshops facilitated by PRIME researchers were conducted using the Theory of Change framework in order to design a mental health care plan tailored for the district and generated through participation of stakeholders who would be involved in implementation. The intervention developed in this PhD forms part of this plan and is indicated in Figure 2 (PSR support group facilitated by auxiliary social workers).

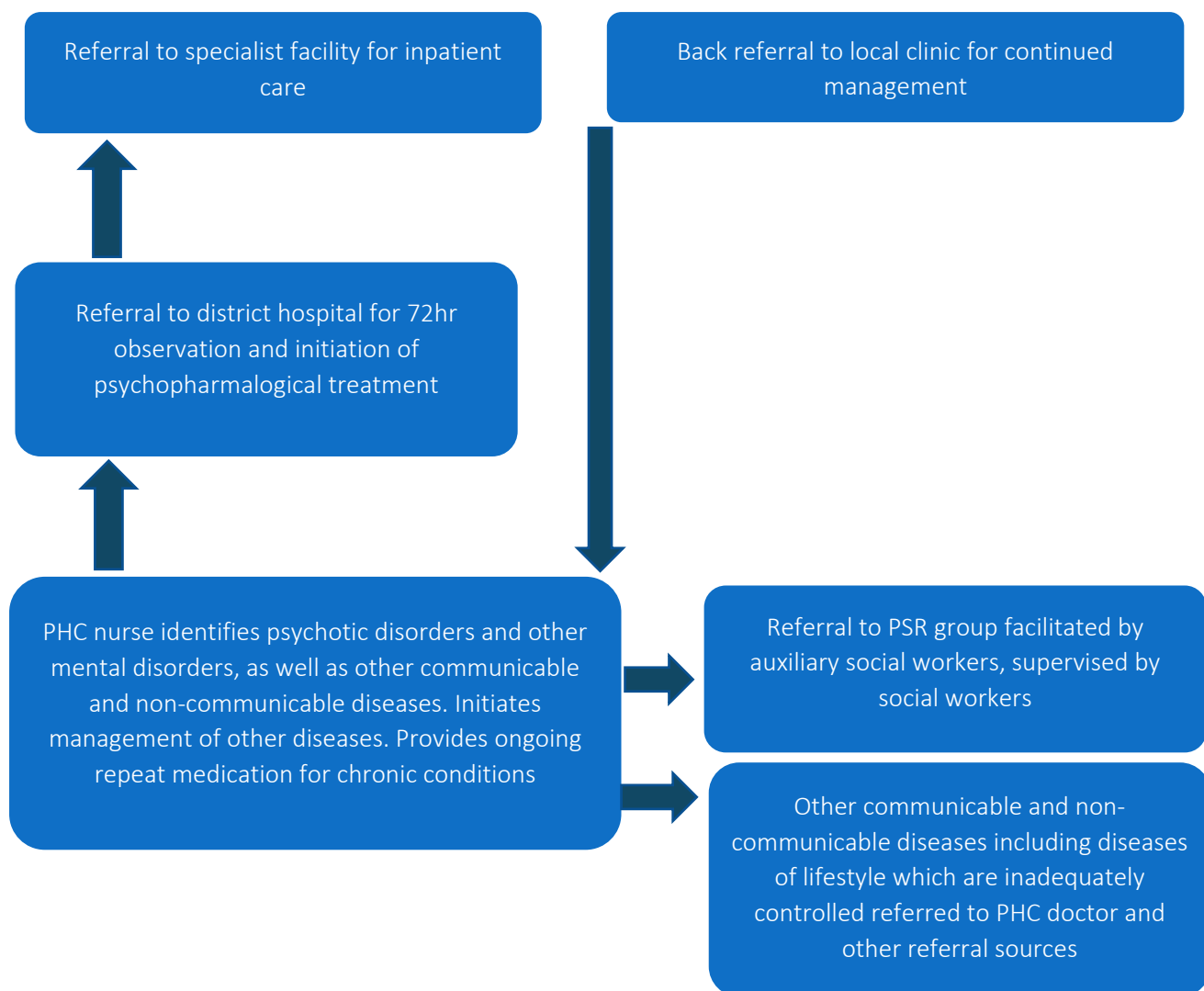


Figure 2. The PRIME- South Africa collaborative care model for schizophrenia

Further intervention work for the PSR intervention included document review and consultation with a psychiatrist and psychiatric nurse providing PSR services in other provinces of South Africa. This, together with the formative work described under Objectives 1 and 2, informed a participatory learning-based Training Manual for a five-day training workshop for Facilitators of the intervention. A structured Facilitator Guide for use by ASWs outlining the process for each group session was also developed. The intervention comprised 12 facilitated sessions for service users (to be delivered weekly over three months) and five sessions for caregivers.

Session topics are given below and the manuals can be found in the appendices of this thesis. These materials were developed by the candidate, with input from supervisors and experts in the field. An additional output of the intervention was an information leaflet on schizophrenia, developed by the candidate, which was given to service users for their use and for sharing with families and other contacts (Appendix 1).

Service user sessions:

- Introduction to Programme and Goal Setting
- Understanding Our Schizophrenia Diagnosis
- Understanding Medication
- Coping with Schizophrenia
- Substance Abuse
- Knowing Ourselves
- Income Generating Activities
- Managing Anger, Stress and Conflict
- Dealing With Stigma and Discrimination
- Contributing to the Household
- Money Management
- Closure Session

Caregiver sessions:

- Understanding Our Relative's Illness
- Coping With Caring for A Person With Schizophrenia
- The Effect of Conflict in the Family
- Dealing with Stigma and Discrimination

- Caring for the Caregiver

Objective 4: Paper 3: Formative evaluation of a community-based psychosocial rehabilitation programme for schizophrenia service users in the North West Province of South Africa

Authors: Carrie Brooke-Sumner, Crick Lund, One Selohilwe, Inge Petersen (submitted, Social Work in Mental Health)

There is currently little implementation research in South Africa for community-based PSR programmes delivered in partnership with locally based NGOs – the model of service delivery employed in this study. This paper aimed to deliver the intervention developed and conduct a formative evaluation to determine preliminary qualitative outcomes, acceptability and implementation challenges.

Author contributions: CBS developed the intervention manual, co-facilitated training, oversaw data collection, conducted analysis, and prepared first through to final drafts. IP reviewed the intervention manual, provided overall management for the research process, advised on analysis. CL reviewed the intervention manual, advised on analysis, and reviewed first through to final drafts. OS reviewed the intervention manual, managed participant recruitment and other research processes on site, co-facilitated training, conducted functional assessment. All authors approved first through final drafts.

This paper adds to the limited evidence on task-sharing interventions for schizophrenia in LMIC and South Africa specifically. Challenges related to lack of resources emerged as a significant constraint to implementation. Sustainable provision of adequate resources for PSR

in South Africa is a major underlying challenge requiring inputs from the government departments mandated for provision of this service. Collaboration between these sectors (notably DOH and DOSD) has previously been identified as a limiting factor in this regard. Paper 4 aimed to investigate this challenge and make recommendations for promoting intersectoral provision of PSR in South Africa.

Objective 5: Paper 4: Bridging the gap: challenges and way forward for intersectoral provision of psychosocial rehabilitation in South Africa

Authors: Carrie Brooke-Sumner, Crick Lund, Inge Petersen (submitted International Journal of Mental Health Systems)

The Health, Social Development and NGO sectors are clearly mandated in South African policy as key role players in the provision of PSR but levels of service provision vary widely across provinces. The Health sector is responsible for provision for biomedical treatment, but also through National Mental Health Policy, to provide rehabilitation services. The Social Development sector is similarly mandated for community based rehabilitation, covering social case work needs of people with psychosocial disability as well as overall community development. NGOs as the organisations on the ground are key in being well placed within communities to provide services to those with psychosocial disabilities. This paper aimed to investigate challenges to intersectoral working between DOH, DOSD and NGO sectors for the provision of community-based PSR services and to gain perspectives from key informants on strategies for addressing challenges. Data collection for this part of the PhD was nested within the larger EMERALD study (Emerging mental health systems in low- and middle-income countries) which is reflected in the informed consent documentation and ethical clearance.

Author contributions: CBS conceptualised the study, the design of interview schedules, conducted some interviews, conducted qualitative analysis, drafted and revised manuscript. CL advised on analysis and critically reviewed drafts of the manuscript. IP contributed to conceptualisation of the study and interview schedules, contributed to analysis and critically reviewed drafts of the manuscript. All authors approved first through final drafts.

Ethical considerations

Permission was granted for this study from the University of KwaZulu-Natal and the University of Cape Town, as part of the PRIME ethical approval (UKZN HSS/0623/012D; UCT HREC 412/2011, Appendix 2) and for the intersectoral collaboration investigation under the EMERALD study (UKZN BE407/13). Gatekeeper approval for PRIME research was obtained from the provincial Department of Health. Participants (service users, caregivers, service providers, key informants from DOH, DOSD, NGOs) were advised of the voluntary nature of their participation and of their right to withdraw from the study at any point. All participants provided written informed consent and permission to report findings, following an explanation of the research, in SeTswana for those not fluent in English. All personal identifying information was removed from the data. Hard copies of interview transcripts were stored in a locked office and soft copies were stored on password-locked computers of three members of the PRIME research team. Specific ethical considerations are set out in more detail in each paper and informed consent forms are in Appendix 3.

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Chapter 2: Paper 1: Systematic review of feasibility and acceptability of psychosocial interventions for schizophrenia in low and middle income countries

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Paper 1: Systematic review of feasibility and acceptability of psychosocial interventions for schizophrenia in low and middle income countries

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Abstract

Background

In low and middle income countries there is evidence to suggest effectiveness of community-based psychosocial interventions for schizophrenia. Many psychosocial interventions have however been conceptualized in high income countries and assessing their feasibility and acceptability in low and middle income countries is pertinent and the objective of this review.

Methods

Six databases were searched using search terms (i) “Schizophrenia”; (ii) “Low and middle income or developing countries” and (iii) “Psychosocial interventions”. Abstracts identified were extracted to an EndNote Database. Two authors independently reviewed abstracts according to defined inclusion and exclusion criteria. Full papers were accessed of studies meeting these criteria, or for which more information was needed to include or exclude them. Data were extracted from included studies using a predesigned data extraction form. Qualitative synthesis of qualitative and quantitative data was conducted.

Results

14 037 abstracts were identified through searches. 196 full articles were reviewed with 17 articles meeting the inclusion criteria. Little data emerged on feasibility. Barriers to feasibility were noted including low education levels of participants, unavailability of caregivers, and logistical issues such as difficulty in follow up of participants. Evidence of acceptability was noted in high participation rates and levels of satisfaction with interventions.

Conclusion

While there is preliminary evidence to suggest acceptability of community-based psychosocial interventions for schizophrenia in low and middle income countries, evidence for overall feasibility is currently lacking. Well-designed intervention studies incorporating specific measures of acceptability and feasibility are needed.

Background

Schizophrenia is a chronic and highly disabling mental illness that contributes 15.2 million Disability Adjusted Life Years to the burden of disease in low and middle income countries (LMIC) (Collins et al., 2011). Access and adherence to pharmacological treatment is key to improving symptoms and functionality and reducing relapse rates. There is consensus that psychosocial interventions are also an important component of care for schizophrenia. A body of evidence has developed in high income countries (HIC) on five main approaches: psychoeducation (Xia et al., 2011), family interventions (Pharoah et al., 2010), intensive case management (Dieterich et al., 2010), cognitive rehabilitation (McGrath & Hayes Robyn, 2000) and social skills training (Tungpunkom et al., 2012). These interventions show reasonable levels of effect on outcomes including relapse prevention, reducing hospital readmission and promoting medication adherence. Within LMIC, community-based rehabilitation, psychoeducation and support for families (delivered by non-specialists) are recommended for low resource settings, with assertive community care and cognitive therapy recommended as additions in higher resourced settings with stronger service-delivery platforms (Mari et al., 2009). A recent systematic review of

randomized controlled trials for psychosocial interventions for schizophrenia in LMIC suggested evidence for positive effects on social functioning but highlighted a lack of evidence from high quality trials (De Silva et al., 2013). Studies not included in that review (e.g., non-randomized studies and those with outcomes other than social functioning) also suggest effectiveness of psychosocial interventions in LMIC (for example family interventions in Iran (Koolae & Etemadi, 2010b), community-based rehabilitation in India (Chatterjee et al., 2003; Chatterjee et al., 2009), modified assertive community treatment in South Africa (Botha et al., 2010), and social skills training in Mexico (Valencia et al., 2007)).

Feasibility as a construct in public health practice incorporates a variety of aspects of intervention delivery. These include demand (is the intervention taken up?), implementation (can it be delivered as planned?), practicality (can it be delivered despite constraints, e.g., of resources and time?) (Bowen et al., 2009). In addition it incorporates acceptability, or how the recipients of (or those delivering) the intervention perceive and react to it (Bowen et al., 2009). Assessing the feasibility in LMIC of interventions that have been developed in HIC is particularly pertinent given the variation in available resources and cultural contexts. Furthermore, a critique of some psychosocial interventions has been that their development has been led by service providers, who may lack insight into service users' perspectives (Wai Tong Chien, 2013). Information on feasibility, despite being crucial for effective resource allocation, is under-reported in intervention studies (Bird et al., 2013). Progress has been made on systematising assessment of feasibility in mental health services in HIC [e.g., Structured Assessment of FEasibility (SAFE)] (Bird et al., 2013). However, this approach has yet to be applied extensively in LMIC contexts. The scarcity of resources for mental health services in LMIC, particularly at community level, is well known (Saraceno et al., 2007). The question of feasibility of delivering psychosocial interventions in resource-constrained settings therefore

remains. This study aims to systematically assess the evidence for feasibility and acceptability of community-based psychosocial interventions for schizophrenia in LMIC, and to generate recommendations for practice and priorities for future research.

Methods

Six databases were searched in February 2013 – Medline, Embase, PsychInfo, Global Health, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and the Cochrane Library. Search terms combined three concepts: (i) “Schizophrenia”; (ii) “Low and middle income or developing countries” as defined by World Bank criteria at the time of the study; and (iii) “Psychosocial interventions”. The third concept was expanded in various ways according to the database searched. Interventions captured within this concept included: “Psychotherapy”, “psychoeducation”, “adherence”, “rehabilitation”, “health promotion”, “collaborative care”, “family interventions” and “self-help”. Tailored searches were developed for each of the databases as detailed in Appendix 1, using MeSH terms in Medline and equivalent terms when available in other databases. “Acceptability” and “feasibility” were not included as terms in the search strategy. Their inclusion could have reduced the number of abstracts identified, and potentially missed studies that reported on aspects of acceptability and feasibility without specifying this terminology. Community-based intervention for the purposes of this review was defined as an intervention delivered to a person residing in the community rather than in a hospital or other health care facility. The intervention may be delivered at the patient’s home, in a health centre, hospital outpatients’ clinic or other facility. Psychosocial has been defined as an intervention that focuses on psychological, behavioural or social factors, rather than biological factors. For inclusion and exclusion criteria, see Table 1.

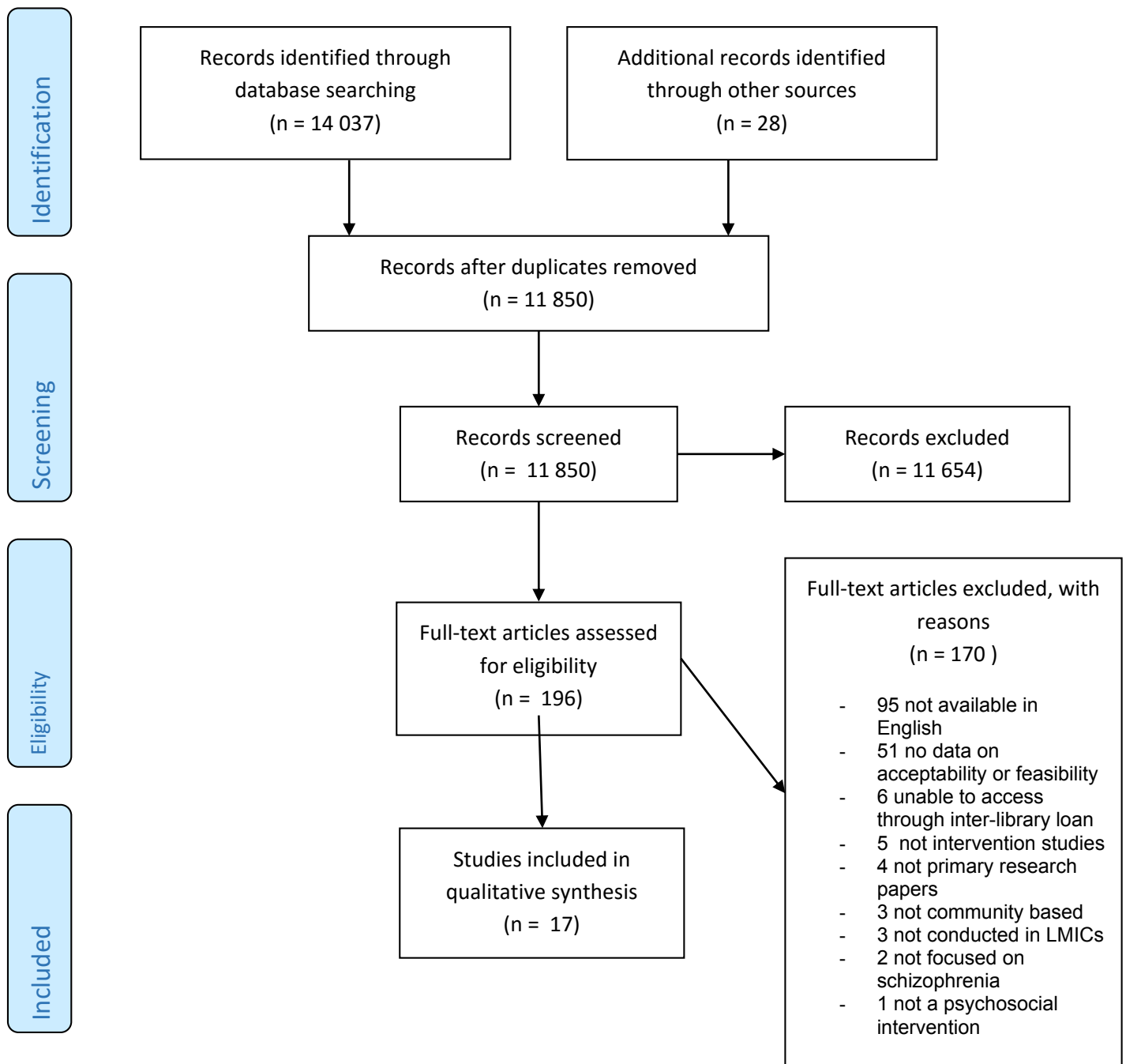
Table 1 Inclusion and exclusion criteria

	Included	Excluded
Publication type	English Language Any date	Non-English articles Editorials, review articles, letters, practice guidelines, other guideline documents, conference abstracts, conference reports, news articles. Grey Literature, Baseline studies
Study design	Any study design for primary research that included information relating to the acceptability and/or feasibility of a community-based psychosocial intervention for people with schizophrenia and/or their families and caregivers.	
Study population	General adult population. Study conducted in LMIC as defined by the World Bank at time of study.	Interventions for children and adolescents (< 18 years). Study conducted in HIC.
Condition of interest	Schizophrenia or schizoaffective disorder only.	Other mental disorders (depression, substance abuse, bipolar disorder, anxiety disorder). Epilepsy, other types of disability. Brief psychotic disorders.

Intervention	Any community-based psychosocial intervention delivered to people with schizophrenia or their caregivers.	Pharmacological interventions Interventions for hospital in-patients.
Outcome	Any quantitative or qualitative measure from service users or care givers showing acceptability and/or feasibility of the psychosocial interventions.	Effectiveness data, when not accompanied by data on acceptability and feasibility.

Abstracts identified were extracted to an EndNote Database (14 037 abstracts) (See Figure 1). Relevant researchers were contacted, and reference lists reviewed to identify further studies. CBS and SM independently reviewed the abstracts according to the inclusion and exclusion criteria. Full versions of studies meeting these criteria, or for which more information was needed in order to include or exclude, were accessed (196 full text articles). CBS reviewed these studies in full. SM and COE checked for agreement on included and excluded studies. Data were extracted using a standard form, with data extraction performed by CBS and COE independently (see Appendix 2). These authors then agreed on the final data to be included in the analysis.

Figure 1: PRISMA flowchart for systematic review process



Quality of the included studies was assessed by CBS and COE independently using the Effective Public Health Practice Project (EPHPP) Quality Assessment for Quantitative Studies (Project, 2008), which enables assessment of selection bias, appropriateness of study design,

the level of confounding, use of blinding, and the appropriateness of data collection methods and data analysis (see Appendix 3). For qualitative studies the Critical Appraisal Skills Programme (CASP) checklist was used. This tool assesses the appropriateness of the methodology, research design, recruitment strategy, data collection and analysis, and influence of the relationship or bias of the researcher (see Appendix 3). Owing to the small number of studies and limited reporting on acceptability and feasibility, the quality assessment was used to guide understanding of the relative strengths of the evidence rather than to exclude studies (Dissemination, 2008).

Data Analysis

Qualitative synthesis

Data analysis encompassed a qualitative synthesis (thematic synthesis) of qualitative and quantitative data (Thomas & Harden, 2008). This method is a three-step process involving (i) free coding of data from included studies; (ii) organisation of free codes into related areas or “descriptive themes” and (iii) inferring “analytical” themes which go beyond the findings of the original studies (Suri & Clarke, 2009; Thomas & Harden, 2008) . Studies of weak or unknown quality were not included in the initial analysis but were revisited after analysis of high quality studies to search for additional themes or supporting data. No additional themes emerged, however, supporting data for existing themes were included in this way. Several strategies were adopted to reduce possible bias. Firstly, coding was inductive rather than using an *a priori* framework. Secondly, analytical themes were generated through consensus amongst the authors. In the full article review, nine articles describing seven studies reported anecdotally on feasibility and acceptability. The concepts identified in these anecdotal reports were not operationalised as part of the data collection, however, the data from these studies was used in support of the already identified themes.

Results

Characteristics of included studies

Seventeen articles from 17 separate studies were included in the review. The main characteristics and quality assessments for these studies are presented in Table 2. The included studies were from 11 countries in Asia, Africa, South America, the Middle East and Eastern Europe. The studies presented a wide variety of settings, locations and designs as described in Table 2. Interventions in the included studies are described in Table 3.

Table 2 Summary characteristics of included studies

Variable	Number of Studies	%
Setting		
Out-patient clinic	11	65%
Community health/rehabilitation centre	3	18%
Home-based	2	12%
Not reported	1	5%
Location		
Urban	13	80%
Rural	1	5%
Rural and urban	1	5%
Not reported	2	10%
Intervention Target		

Individual (patient)	5	30%
Family/caregiver	6	35%
Patient and caregiver	6	35%
Implementation workforce		
Lay worker	2	10%
Specialist	12	71%
Not reported	4	19%
Study Design		
Randomised Controlled Trial	5	30%
Cohort	3	19%
Cross sectional	4	21%
Qualitative	5	30%
Quality assessment		
Quantitative		
Adequate	11	85%
Weak/unknown	2	15%
Qualitative		
Adequate	4	100%
Weak/unknown	0	0%

Table 3 Description of included studies

Country (Author, date)	Study design	Intervention	Intervention workforce	Sample	Measures of acceptability and feasibility identified
1. China (Xiong et al., 1994 [40])	Randomised controlled trial (RCT)	1. Monthly 45 minute counselling sessions with patient and family 2. Family group therapy sessions	Therapist	63 families 34 in intervention group 29 in control group	Compliance
2. China (Ban et al., 2003 [27])	RCT	1. Monthly family visit incorporating psychoeducation 2. Family workshops 3. Crisis intervention	Therapist	326 patients and families 126 cases in family intervention group 103 cases in pharmacological treatment group 97 cases in control group	Reasons for refusal to participate
3. Poland (Slupczynska-Kosobudzka et al., 1999 [36])	Cohort	1. Medication management 2. Individual psychotherapy 3. Daily living and social skills training 4. Therapeutic work with family 5. Welfare assistance	Multidisciplinary team: psychiatrist, psychologist, 3 nurses, social worker	88 patients and families	Satisfaction scale
4. Turkey (Tas et al., 2012 [35])	Randomised pilot study	1. Family-assisted social cognition and interaction training (14-session group training)	Family members trained as "cognition partners"	45 patients and 45 family members	Satisfaction scale
5. China (Zhang et al., 1993 [49])	Cohort	1. Family psychoeducation (10 lectures, 3 discussion groups)	Psychologist	3092 patients	Participation rates
6. China (Zhang et al., 1994 [25])	Cohort	1. Family counselling 2. Home visits for non-attenders	Counsellors	83 patients and family	Description of feasibility issues
7. Egypt, (Gohar et al., 2013 [33])	RCT	1. Social cognition training (2 sessions per week for 8 weeks)	Psychiatrist	42 patients 22 in intervention group 20 in control group (skills training intervention)	Satisfaction scale
8. Poland (Chadyńska et al., 2011 [37])	Cross-sectional	1. Group psychoeducation sessions	Therapist	167 patients	Questionnaire covering opinions on sessions
9. Chile (Caqueo-Urrázar et al., 2009 [39])	Cross-sectional	1. Multifamily intervention programme for caregivers – 18 weekly sessions (psychoeducation and living skills)	Not reported	41 primary caregivers	Satisfaction questionnaire
10. India (Kulhara et al., 2009 [32])	RCT	1. Manualised psychoeducation intervention for carers (monthly sessions of 1 hr)	Mental health professionals	38 patients and caregivers in both experimental and control groups	Satisfaction questionnaire
11. Brazil (Cabral et al., 2010 [29])	Cross-sectional	1. Weekly psychoeducational and supportive therapy group for patients 2. Weekly psychoeducational multi-family group	Not reported	44 primary caregivers	Opinion questionnaire and satisfaction scale

Table 3 Description of included studies (Continued)

12. Thailand (Worakul et al., 2007 [34])	Cohort	1. Family psychoeducational programme (1 day programme didactic component and group discussion)	Psychiatrists	91 primary caregivers	Satisfaction scale
13. Czech Republic (Moclova et al., 2006 [38])	Prospective follow up study	1. Outpatient clinic based psychoeducation intervention for patients and family	Professionals (not specified)	53 patients, 98 family members	Outcome questionnaire
14. India (Balaji et al., 2012 [23])	Qualitative	Collaborative community-based care: 1. Psychoeducation 2. Adherence management 3. Rehabilitation 4. Referral to community agents	Community lay health workers	In-depth interviews with 32 patients, 38 caregivers	Qualitative
15. Brazil (Zimmer et al., 2006 [24])	Qualitative	1. CBT incorporating cognitive differentiation, social perception, verbal communication, social skills, interpersonal problem solving	Not reported	22 patients' expressions of perceptions of intervention (written and verbal accounts)	Qualitative
16. South Africa (Pope et al., 2010 [43])	Qualitative	1. Patient psychoeducation	Not reported	Focus groups with 9 in-patients 9 out-patients (study did not disaggregate in analysis) Semi-structured interviews with 15 patients	Qualitative
17. South Africa (Asmal et al., 2013 [41])	Qualitative	1. Family therapy – multi family groups of schizophrenia patients and caregivers	Psychiatric nurse	Semi-structured interviews, 20 patients and 20 family members	Qualitative

This study did not aim to review effectiveness or efficacy of the included interventions. However, it is relevant to report on the effectiveness and/or efficacy data that were present in included studies since an intervention may be acceptable and feasible, but have little or no effect. Of the 17 studies included, 11 included data on efficacy or effectiveness (see Appendix 2). These data indicated positive effects on outcomes such as rehospitalisation rates (Motlova et al., 2006; Slupczynska-Kossobudzka & Boguszezwska, 1999; Xiong et al., 1994b; Zhang et al., 1994; Zhang et al., 1993), relapse rates (Ran et al., 2003; Xiong et al., 1994b; Zhang et al., 1993), medication adherence (Ran et al., 2003; Zhang et al., 1993), social functioning (Gohar et al., 2013; Slupczynska-Kossobudzka & Boguszezwska, 1999; Tas et al., 2012), quality of life (Tas et al., 2012), symptomatology (Kulhara et al., 2009; Tas et al., 2012; Zhang et al., 1994), disability (Kulhara et al., 2009) and knowledge of the illness (Cabral & Chaves, 2010; Worakul et al., 2007). Some studies, however, showed little effect, for example on certain aspects of social functioning (Tas et al., 2012) and on working status (Zhang et al., 1994). Similarly, in a study conducted by Worakul *et al.*, small statistically significant improvements in knowledge of the illness, and no improvement in attitude to the illness following a psychoeducation programme, were reported (Worakul et al., 2007).

Outline of results of data synthesis

The limited data on feasibility available from the studies fell under the theme “barriers to feasibility”. Four themes on acceptability emerged, (i) participants’ satisfaction with the intervention (with a variety of measures used to assess satisfaction); (ii) participation rates; (iii) barriers to acceptability; and (iv) facilitators of acceptability. It was noted in the analysis that themes identified were not distinct. For example, fear of stigma as a barrier to acceptability could also be a barrier to feasibility.

1. Barriers to feasibility

Education level of participants

Two studies cited low levels of education or literacy as a challenge to feasibility. In an Indian collaborative community-based care programme reported on by Balaji *et al.*, five out of 30 participants could not read, rendering psychoeducational materials inappropriate. However, replacing reading components with verbal explanations was feasible (Balaji *et al.*, 2012). A Brazilian cognitive behavioural therapy (CBT) programme reported participants having difficulty with writing activities and taking instructions for activities to be done at home (Zimmer *et al.*, 2006). The authors suggested a link between low levels of schooling of participants and low motivation for verbal communication tasks (Zimmer *et al.*, 2006).

Logistical issues

Three studies reported on logistical challenges to feasibility. Balaji *et al.* in India noted difficulties in the roll-out of their collaborative community-based care programme in that out of 43 patients who consented to be involved only 30 received the intervention because 13 were unreachable or had been hospitalized (Balaji *et al.*, 2012). Yet the programme itself was considered feasible as there was only one case in which a participant could not afford to travel to an intervention worker to receive care (Balaji *et al.*, 2012). In a Chinese family counselling programme, five out of 42 patients were lost to follow up due to moving out of the district or leaving the parental home (Zhang *et al.*, 1994). An Iranian programme involving the training of family members to be case managers for patients with schizophrenia reported anecdotally on concerns for the safety of case managers providing home visits. However, during the year of implementation no dangerous incidents were recorded (Malakouti *et al.*, 2009).

Availability of caregivers

Five studies reported on the unavailability of caregivers either as part of the results of the study, or anecdotally in the discussion. Balaji *et al.* reported that 25% of caregivers were employed or could not be involved for other reasons (Balaji *et al.*, 2012). In China, Ran *et al.* reported that of those patients who declined to participate in a programme of home-based psychoeducation and family workshops (8.7%) the majority (77.4%) did so because they had no family member who could participate (Ran *et al.*, 2003). In line with these findings a psychosocial intervention for mothers of schizophrenia patients in Iran reported anecdotally that half of eligible mothers refused to participate either because it was inconvenient to attend group sessions, because they were not interested, or because there was no one else who could look after their child while they were away (Koolae & Etemadi, 2010a). Similarly, in a Brazilian multi-family group intervention family members who worked were unable to attend as groups took place in the morning. However, for each of the 46 patients, at least one relative attended six or more sessions (total number of sessions not reported) (Cabral & Chaves, 2010). Anecdotal reporting of a psychoeducation programme for caregivers in Malaysia suggested the lack of participation of female caregivers in the programme could be due to the requirement that they stay at home to care for their family member with schizophrenia (Paranthaman *et al.*, 2010).

Resource constraints

Only two studies related feasibility to resource constraints anecdotally. The first suggested that lack of resources for mental health, particularly for training the required personnel, was a key challenge to the implementation of a social skills training programme in Peru (Sotillo *et al.*, 1998). The second reported that involving non-medical personnel, who were appropriately trained and supervised, reduced the costs of the psychoeducation programme for caregivers in

India (estimated cost US\$ 25 per family unit) (Kulhara et al., 2009), making it feasible in this low resource setting.

2. Acceptability

Participants' satisfaction with intervention

Ten studies reported either quantitative or qualitative data on participant satisfaction. These data indicated overall good levels of satisfaction. Two studies (in Turkey and Egypt) of social cognition training showed average satisfaction scores above 8 (10 = excellent) (Gohar et al., 2013; Tas et al., 2012). Similarly the Indian study of psychoeducation for carers showed high satisfaction (mean score 11.8, SD 0.8; 12 = highest satisfaction) (Kulhara et al., 2009). Participants in a Thai study of a family psychoeducation programme rated their levels of satisfaction 3 or above out of 5 (Worakul et al., 2007) and a Polish study of a multicomponent intervention (medication management, psychotherapy, social skills training) showed less than 10% dissatisfaction for nine dimensions assessed (Slupczynska-Kossobudzka & Boguszewska, 1999). In the Brazilian multi-family group therapy intervention the majority of family members found the meetings useful (85%), well organized (75%), and that they helped them to cope with their relative's illness (99%) (Cabral & Chaves, 2010). The majority also found the multi-family model an acceptable format (Cabral & Chaves, 2010). Similarly a Polish study of therapist-delivered group psychoeducation reported that 84% of patients had a positive attitude towards sessions (Chadzynska & Charzynska, 2011). A Czech study of an outpatient clinic-based psychoeducation intervention for patients and family showed patients acknowledged the importance of the information they gained, the value of sharing experiences and also welcomed relatives being involved (Motlova et al., 2006).

Some studies reported lower levels of satisfaction. In Chile family members in a multifamily psychoeducation and skills building programme showed high levels of satisfaction with the progress of their family member, although overall satisfaction with the service provided was higher in the study control group (a waitlisted group receiving usual care) (Xiong et al., 1994a). The Brazilian CBT study showed good patient satisfaction with training on social perception, social skills and problem solving but low levels of satisfaction with abstract activities on cognitive differentiation and verbal communication (Zimmer et al., 2006).

Participation rates

Three studies reported participation rates ranging from high to moderate levels. High participation was reported in a Chinese family psychoeducation programme (10 lectures, three discussion groups: 90.3% of participants attended five or more sessions) (Zhang et al., 1993). A Chinese programme of home-based psychoeducation and family workshops reported an 8.7% refusal rate for those invited to join the programme, and although the refusal rate is a different measure to the participation rate, the former suggests high rates of participation (Ran et al., 2003). A South African study of multi-family group therapy reported moderate overall participation of 79.5% among relatives and 70.5% among patients (Asmal et al., 2013). The investigators reported several measures to encourage participation. Sessions were arranged to coincide with scheduled clinic treatment, the study coordinator reminded relatives of sessions by telephone the day before, and participants were reimbursed for their travel costs (Asmal et al., 2013). A Chinese programme of individual counselling sessions with patients and family group sessions showed similarly moderate rates of participation, with 23% of patients and 27% of families defined as non-compliant (did not attend sessions and refused home visits) (Xiong et al., 1994a).

Barriers to acceptability

Fear of stigma

Among family members and patients, fear of stigma linked with the disclosure of diagnosis was reported in four studies. In the Chinese programme of home-based psychoeducation and family workshops, of the 8.7% of people who refused to participate, 22.6% cited fear of social stigma as the reason (Ran et al., 2003). Again in China, Xiong *et al.* reported that even with regular contact, 32% of families never attended family group meetings because of fear of discovery of their relative's illness (Xiong et al., 1994b). Fears of "gossip and ridicule" in the community were common in the collaborative community-based care programme in India (Balaji et al., 2012).

Lack of appreciation of intervention benefits

Balaji *et al.* reported that 24 of 67 families declined to participate as they were "not interested" or thought the intervention would not be helpful (Balaji et al., 2012). Misunderstanding and suspicions that home visits would be used to try to convert the families to Christianity were voiced. In Brazil, Zimmer *et al.* found that schizophrenia patients could not relate some training exercises to their day-to-day lives and therefore did not fully grasp the benefits of aspects of the CBT intervention (Zimmer et al., 2006).

Facilitators of acceptability

Appropriateness of intervention content and materials

Two studies highlighted the importance of appropriate content from the perspective of participants. The Polish group psychoeducation study indicated patients found several psychoeducation topics to be important but difficult to engage with (e.g., coping with symptoms, asking for help, causes of illness) (Chadzynska & Charzynska, 2011). South

African participants in the multi-family group therapy study found the content of sessions to be “relevant and accessible” but patients and relatives were interested in different topics. For example, patients were interested in discussing loneliness and substance abuse, whereas relatives were interested in dealing with their family members’ challenging behaviour (Asmal et al., 2013).

Four studies reported on the appropriateness of materials. Patients and therapists in the Polish group psychoeducation study found illustrations, photos and charts to be most helpful and suggested the use of video and internet resources (Chadzynska & Charzynska, 2011). Similarly, South African patients assessing the adaptation of psychoeducational materials found the original written materials complicated due to technical language, but said that simplification and using illustrations and examples improved their ease of use (Pooe et al., 2010). In the Polish study, patients found task books and “tests” to assess their knowledge least acceptable (Chadzynska & Charzynska, 2011). Similarly, a Mexican study of psychosocial skills training for patients noted anecdotally that inclusion of written tasks and “homework” was highly unacceptable, causing participants to feel anxious (Valencia et al., 2007).

Health worker characteristics

Three studies reported on the relevance of personal attributes of those delivering the intervention. Characteristics of health workers were key to improving acceptability of collaborative community care in India. Participants had a preference for female workers, and expected them to be well-trained and knowledgeable on the illness (Balaji et al., 2012). Anecdotal reports from the same programme showed fluency in local dialects and knowledge of the cultural context to be important (Chatterjee et al., 2003). The Polish group psychoeducation study showed being “capable of listening and talking” followed by being

“trustworthy”, “effective”, “communicating in a clear and straightforward way”, “patient” and “having extensive knowledge” as the most important characteristics (Chadzynska & Charzynska, 2011).

Discussion

This study reports on feasibility and acceptability from 17 studies of psychosocial interventions for schizophrenia in 11 LMIC. The small number of included studies stemming from the original search strategies (17 articles from 14 037 abstracts reviewed), speaks to the limited nature of the current evidence base. Implementation of psychosocial interventions is a complex process, embedded in and dependent on the context in which it takes place (Bird et al., 2013), yet reporting of contextual factors, recognized as key to development of mental health interventions in LMIC (Patel et al., 2011), was limited in studies in this review. The aim of the review was not to report on efficacy/effectiveness, and studies reporting only on this aspect were excluded. Overall, however, the included studies do suggest important benefits for these interventions on a variety of outcomes, pointing to the relevance of research into factors affecting feasibility and acceptability.

Only one paper (Balaji *et al.*) (Balaji et al., 2012) reported extensively on acceptability and feasibility as operationalised constructs. The level of anecdotal reporting on acceptability and feasibility (nine papers) suggests acknowledgement by investigators of the importance of acceptability and feasibility, however, there remains a lack of operationalisation of these elements in research design. This may reflect a researcher bias towards assessing effectiveness with a lack of attention to patient perspectives and contextual factors (Wai Tong Chien, 2013).

Most studies in this review were based in outpatient clinics, and over 50% were delivered by specialists (Table 1), so despite the positive effects noted, the overall question of the feasibility of these interventions remains for settings with shortages of mental health specialists. The included studies are also overwhelmingly in urban areas. Given recent suggestions that non-specialist delivered psychosocial interventions for schizophrenia may be most suitable as an “initial” service where resources and services are scarce (such as in rural areas) (Chatterjee et al., 2014), lack of focus on rural populations and non-specialist delivered interventions represents an important gap in the evidence.

Overall, evidence on feasibility identified in this review is limited. A recent study of acceptability and feasibility of task sharing interventions for mental health care found ongoing supportive supervision and adequate training and compensation to be crucial for feasibility (Mendenhall et al., 2014). The lack of data identified in this review relating to implementation factors such as training, support, supervision and costing is an important gap and is a challenge in intervention development in this, as in other health areas (Bird et al., 2013). All of these implementation factors are directly impacted by the availability of resources (financial, human, and other), well known to be a crucial impediment to the provision of mental health services in LMIC. The lack of reporting on resources required for these psychosocial interventions therefore presents a particular stumbling block to the development of the field in terms of generating evidence of effectiveness of these interventions, to say nothing of scaling up of effective and acceptable interventions to reach populations in need. The report of cost by Kulhara *et al.* (Kulhara et al., 2009) is important in this regard as it illustrates the financial feasibility of a psychosocial intervention in a LMIC context. Without more reporting of financial feasibility, the perception that psychosocial interventions for schizophrenia are the

realm of specialists, and therefore prohibitively resource-intensive for LMIC settings, may prevail.

Barriers to feasibility emerged in the review, including education levels of participants and availability of caregivers. A significant challenge seems to be maintaining contact with participants over time. This may be particularly relevant for people with schizophrenia who may suffer relapse and be hospitalised, and whose families face multiple stressors including lack of support from other family members, their own illnesses, poverty and lack of access to services.

In relation to acceptability, psychosocial interventions for schizophrenia seem to be generally well accepted by patients and families, indicated by moderate to high levels of participation. However satisfaction (measured with satisfaction scales) and participation rates are open to criticism as markers of acceptability due to the many factors (largely unreported) that may affect satisfaction and participation rates (e.g., desired outcomes, incentives, accessibility of intervention site).

Based on data from the review, the imperative for researchers in the field is operationalisation of feasibility and acceptability as constructs in research designs of pragmatic trials of psychosocial interventions for schizophrenia. The following preliminary recommendations are also made with respect to guiding intervention development to enhance feasibility and acceptability:

1. Understanding context

Some elements of psychosocial interventions such as improving empathy of service providers towards service users and providing psychoeducation may be universal . However, other

elements, such as expressed emotion may vary amongst cultural groups (Asmal et al., 2011). This review found variation in participation rates in China for different intervention types (psychotherapy versus psychoeducation), with investigators suggesting this could be explained by the lack of acceptance in this context of “talking therapy” as an effective tool for improving schizophrenia (Xiong et al., 1994a). This illustrates how detailed understanding using qualitative methodologies of participants’ perspectives, needs and desired outcomes, as well as the social environment, is vital (Patel et al., 2011). This review found personal characteristics of those delivering the intervention to be a driver of acceptability. This aligns well with the recent study of acceptability and feasibility of task sharing for mental health in five countries indicating that understanding the socio-cultural context is essential for identifying appropriate health or other workers to deliver the intervention (Mendenhall et al., 2014).

2. Involving caregivers

Constraints around the involvement of family members were a key barrier to participation in the studies in this review. A detailed and context-specific consideration of how best to engage families (as well as patients) should be a core component of intervention development.

3. Consideration of stigma and discrimination

In this review, fear of stigma was found to be a disincentive to participation. Participating in an intervention identifies a person or family as “mentally ill” and seems to discourage participation. In addition to the societal level work needed to address stigma, those trained to deliver psychosocial interventions need particular guidance in supporting participants to deal with experiences of stigma and discrimination and to minimise the potential of the intervention to increase stigma (e.g., by involuntary disclosure).

4. Use of appropriate materials

This review highlighted that complex written materials or activities that give a sense of testing knowledge discourage participants and reduce acceptability. This indicates the need to adapt

interventions taking into consideration education levels and lived experiences. In low resource settings, an intervention workforce should be trained on how to make the content of material accessible to those who are not able to read or write.

5. Systems for maintaining contact with participants

In addition to the difficulties for follow up introduced by hospitalization or relapse of participants, difficulties with tracing participants may be particularly relevant in LMIC with high levels of mobility amongst communities. Feasibility may be improved by incorporation of an effective system for following up participants should they be hospitalised or move to a different area.

Limitations

There are several limitations to this review due to the developing status of this field of research. Many of the included studies had limited information on how interventions were implemented as this has not yet become the norm for reporting these types of studies. Participation rates have been used in the review as a measure of acceptability, but these may be reduced by accessibility. Since it was not possible to assess accessibility objectively and in a standardized way, the issue of accessibility may have been a significant confounding factor affecting the use of participation as a measure for acceptability. A publication bias may exist and studies showing no or negative effects may have important data on acceptability and feasibility. In addition, the small numbers of participants in many of the included studies may limit the generalisability of findings. Limitations in the process of conducting the review include the exclusion of 95 non-English language articles. A similar review of these non-English language studies would add to these findings, particularly given the dependence of acceptability on cultural factors. Furthermore, traditional, cultural and religious factors are likely to exert a strong influence on acceptability. These factors were not included in the review as data covering these areas was

not found in the included studies. The lack of inclusion of this type of data is an important limitation. The review did not cover effectiveness or efficacy of psychosocial interventions for schizophrenia, and a separate review on this topic is needed. The review also did not report on acceptability and feasibility from the perspective of service providers.

Future research

While the evidence in LMIC for effectiveness of psychosocial interventions for schizophrenia is growing, pragmatic trials are needed of appropriately adapted interventions that focus not only on effectiveness, but also on feasibility and acceptability. Failure to take into account factors impacting on feasibility and acceptability threatens long-term sustainability and disregards the perspectives of patients and their families. Future studies will benefit from in-depth qualitative intervention development work and piloting, and qualitative evaluation to help understand quantitative findings and elucidate barriers to acceptability and feasibility. Future studies should assess participant satisfaction using specifically designed measures based on participants' desired outcomes (e.g., employment, social activity, and fulfillment of responsibilities).

Conclusion

While there is preliminary and limited evidence to suggest acceptability of community-based psychosocial interventions for schizophrenia in LMIC, the evidence for overall feasibility is limited. Important barriers to acceptability and feasibility are the fear of stigma associated with being identified as having a mental illness, or having a family member with mental illness, as well as multiple roles and responsibilities of caregivers making it difficult to engage them in interventions. The field urgently needs well-designed intervention studies incorporating

measures of acceptability and feasibility, as well as development of instruments to measure acceptability and feasibility in diverse cultural settings in LMIC.

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Competing Interests

The authors declare that they have no competing interests.

Author contributions

CBS contributed to development of search protocol, reviewed initial abstract database, conducted analysis, compiled first through final drafts. CL contributed to development of search protocol, advised on inclusion and exclusion and data analysis process, reviewed first through final drafts. IP contributed to development of search protocol, advised on inclusion and exclusion and data analysis process, reviewed first through final drafts. LA contributed to development of search protocol, developed search strategy, conducted database searches, reviewed first through final drafts. SM reviewed initial abstract database, reviewed first through final drafts. COE reviewed included and excluded articles and checked data for inclusion/exclusion, reviewed first through final drafts.

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Chapter 3: Paper 2: Perceptions of psychosocial disability amongst psychiatric service users and caregivers in South Africa

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Perceptions of psychosocial disability among psychiatric service users and caregivers in South Africa

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Abstract

Background: In many parts of South Africa there is little support for people with psychosocial disability caused by schizophrenia, beyond provision of psychotropic medications. Appropriate community-based psychosocial rehabilitation interventions are a crucial element of mental health service development.

Objectives: This study aimed to use an explanatory model of illness framework to document experiences of illness, disability and recovery amongst service users with schizophrenia and their caregivers in a poorly resourced area in the North West Province. Data was used to provide recommendations for a contextually appropriate non-specialist facilitated group psychosocial rehabilitation intervention.

Method:

Eighteen in-depth individual interviews were conducted: 9 with schizophrenia service users and 9 with caregivers. Interviews were conducted by two trained field researchers; both clinical psychologists fluent in the first language of participants. All interviews were recorded, translated and transcribed. Data were thematically analysed using NVivo 9.

Results:

Participants linked the illness to witchcraft, poverty and stress. Family conflict was recognised in the course of the illness causing stress and challenges for emotional wellbeing. Knowledge of diagnosis and biomedical treatment were minimal. Key factors recognised by service users as promoting recovery were the ability to work, and the support of traditional healers and religious structures.

Conclusion:

Based on the findings of this study, a group psychosocial rehabilitation intervention emerged as a recommendation, with the incorporation of psychoeducation, adherence support, coping skills, and opportunities for income generation and productive activity. The importance of also enlisting the support of religious leaders and traditional healers in supporting recovery is emphasized.

Introduction

Schizophrenia can be a chronic, highly disabling mental illness. Its associated disability can significantly undermine a person's ability to function in their social environment. Schizophrenia was given the highest disability rating of all disorders studied in the 2010 Global Burden of Disease study (Whiteford et al., 2013) In the absence of nationally representative epidemiological studies, annual schizophrenia prevalence has been estimated at 1% in one South African province (Western Cape) (Kleintjes, 2006).

Psychosocial rehabilitation (PSR) helps people with schizophrenia on the journey of recovery by helping them gain skills and access resources that improve their capacity to live fulfilling and productive lives (Anthony, 2009). In many parts of South Africa there is however little

support beyond provision of psychotropic medications, which are relatively widely available within primary health services (Lund et al., 2010).

There is a robust evidence base for psychosocial rehabilitation interventions promoting recovery in high income countries (HIC) (e.g. intensive case management (Dieterich et al., 2010), psychoeducation (Xia et al., 2011), interventions with families (Pharoah et al., 2010), life skills training (Tungpunkom et al., 2012), cognitive behavioural therapy (Jones et al., 2011), cognitive rehabilitation (McGrath & Hayes Robyn, 2000)). Growing evidence in low and middle income countries (LMIC) indicates effectiveness of local adaptations of some of these interventions e.g. (Chatterjee et al., 2011) (Balaji et al., 2012) (Ran et al., 2003) (Gutierrez-Maldonado et al., 2009) (Malakouti et al., 2009). Evidence for group-based psychosocial approaches, which may be more feasible than interventions delivered to individuals, is also growing in LMIC, for example group-based psychoeducation in China (Zhang et al., 1998) (Weidong et al., 2010) and the Czech republic (Motlova et al., 2004), group-based social cognition training in Turkey (Tas et al., 2012), group based cognitive rehabilitation in Malaysia (Alwi et al., 2010) and Iran (Ali beigi et al., 2011) and group-based family intervention in Brazil (Cabral & Chaves, 2010) In South Africa, recent studies have shown the potential for assertive community treatment (nurse/social worker led) (Botha et al., 2014; Botha et al., 2010) and group-based family therapy (nurse-led) (Asmal et al., 2013).

Insufficient resource allocation for psychosocial community-based services for recovery is well recognised in South Africa (Coetzee & Kemp, 1982; Lund et al., 2010; Petersen & Lund, 2011). Given the paucity of specialist mental health human resources (0.4 psychologists per 100 000 population; 0.1 social workers and occupational therapists per 100 000 population in the North West province (the site of this study) (Lund et al., 2010), adopting a task sharing approach is

indicated in line with global recommendations (Mari et al., 2009), the recent WHO Mental Health Action Plan (WHO, 2013) and South Africa's National Mental Health Policy Framework and Strategic Plan (2013-2020) (Department of Health, 2013).

Objectives

The biopsychosocial model of disability underlines the effects of mental illness on multiple linked 'domains' of an individual's life (body, mind, and social interaction/participation) (King, 2007). The starting point for intervention is therefore an understanding of the lived experience of schizophrenia and psychosocial disability. This study aimed to document experiences and perceptions of illness, disability and recovery amongst service users with schizophrenia and caregivers, with the view to informing a contextually appropriate community-based psychosocial intervention that could be facilitated by non-specialists within a resource constrained setting.

Contribution to the field

Understanding explanatory models of illness held by psychiatric service users with schizophrenia attending primary health care clinics for symptom management is important to inform the development of a socio-culturally acceptable psychosocial rehabilitation intervention at this level of care that can aid recovery within similar scarce resource contexts in South Africa.

Research Method and Design

Setting

This study is part of The Programme for Improving Mental Health Care (PRIME), a research consortium aiming to generate evidence for implementation of programmes for priority mental

disorders in low resource settings (Lund, 2012). In South Africa, PRIME is a collaboration between mental health researchers and the South African Department of Health (DOH) in Dr Kenneth Kaunda district in the North West Province.

Procedure

Sampling Strategy

Service users were recruited using a convenience sampling approach: (i) through clinic registers from two primary care clinics (5 service users, 5 caregivers), and (ii) through the North West Mental Health Society (4 service users, 4 caregivers). The North West Mental Health Society is affiliated to the South African Mental Health Federation (SAMHF) – a non-governmental organisation (NGO) providing mental health services and administering disability grants. Criteria for inclusion in the study were a confirmed diagnosis of schizophrenia or being a caregiver of a person with a schizophrenia diagnosis, and being over the age of 18. Service users interviewed were people whose symptoms were well managed and who accessed repeat medication from the clinics. The two interviewers were clinical psychologists who used their clinical judgement to establish whether participants were able to give informed consent and participate in the interview. Similarly, clinical judgement was used to assess suitability of caregivers and through this process one caregiver was referred to a psychologist for treatment of her depression.

Data collection

Eighteen semi-structured individual qualitative interviews were conducted, 9 with service users and 9 with their respective caregivers. The interview schedules were based on Kleinman's (Kleinman, 1980) concept of explanatory models of illness (EMI), and covered understanding of causes, experiences of symptoms, course (including experiences of stigma and

discrimination), treatment (including interaction with service providers and experiences with disability grants) and healing/recovery. The interview schedules also included questions on the acceptability of a facilitated group approach. Interview schedules were reviewed and simplified to take into consideration possible lower levels of functioning of interview participants. Interviews were conducted by two clinical psychologists, both first language Setswana speakers and fluent English speakers. One of the interviewers was also training to become a traditional healer, giving her a relevant perspective on issues relating to mental health in the community in question. The interviewers contributed to the development of the interview schedule to ensure consideration of cultural nuances. Interviews were conducted in service users' first language (mainly Setswana, one English interview). All interviews were recorded, and then translated where necessary into English and transcribed.

Analyses

NVivo9 qualitative data analysis software was used to store data and conduct analysis. All interviews were coded by the first author. Framework analysis (Ritchie, 1994) was used involving the following steps. First, the transcripts were read and re-read to familiarize and immerse the researcher in the data. Second, a thematic framework, corresponding to the interview schedules, was generated for sorting data. . Third the transcripts were coded, using the thematic framework developed , with additional themes being added as consecutive transcripts were analysed and new themes emerged. Further review and recoding of transcripts was carried out until no additional themes or subthemes emerged.

Ethical considerations

Permission was granted for this study from the University of KwaZulu-Natal and the University of Cape Town, as part of the PRIME ethical approval (UKZN HSS/0623/012D; UCT HREC

412/2011). Approval for PRIME research was obtained from the provincial Department of Health. Potential participants were informed that there was no direct benefit to them of participating in the interview, other than the small grocery store voucher (R30) incentive. Participants were advised of the voluntary nature of their participation and of their right to withdraw from the study at any point. All participants provided written informed consent and permission to report findings, following an explanation of the research in their first language. The interviews were conducted in a private room and all personal identifying information was removed from the data. Hard copies of interview transcripts were stored in a locked office, and soft copies were stored on password locked computers.

Results

Demographic characteristics of service users are given in Table 1. Demographic information on caregivers was not collected, however all caregivers were female family members.

Table 1 Demographic characteristics of service users interviewed

Demographic	Service Users N= 9	Percentage
Gender: Male	5	55%
Female	4	45%
Age: 18-20	0	
21-30	1	11%
31-40	2	22%
41-59	6	67%

Education:		
No Schooling	2	22%
Primary Education	3	33%
Secondary and Post-Secondary	4	45%
Marital Status		
Not married	5	56%
Married	1	11%
Cohabiting	3	33%
Employment Status		
Employed	1	11%
Unemployed	7	78%
Student	1	11%
Housing		
House	7	78%
Rented Room	2	22%
Number Living in Household		
Under 16 years:		
1-3 people	4	45%
Over 16 years:**		
1 person	0	
2-3 people	6	67%
4-6 people	2	22%
Sources of Household Income		
Grants only	3	33%

Grants and Ad Hoc work	1	11%
Grants and Salary	5	56%

**Data missing for one participant

Seven main themes emerged from the data.

1. Understanding of causes and symptoms

Subtheme 1: Understanding of causes

Participants commonly had more than one understanding of the cause of their illness and impairments. Witchcraft was most commonly believed to be the cause.

‘A person might get naked and walk around the streets undressed due to her mental state that has changed after being bewitched’. – Service user Participant 5

One service user made the link between their illness and the stress caused by living in extreme poverty.

‘People should have money and should be given jobs because if you do not have money, you become stress[ed]. This stress exacerbates your illness. When you have money you don’t become mentally ill’. – Service user participant 2

Two service users identified conflict in their family as a cause of their illness. Three others attributed their illness to an experience of violence; a traumatic brain injury in childhood and smoking cannabis. Three caregivers attributed the illness to witchcraft, with one explaining that it could be due to a ‘calling’ to become a traditional healer. Other caregivers had different explanations - one linked the illness to their family member’s experience of being in prison, two believed that it was a result of pregnancy, and two attributed the worsening of the illness to the seasons.

Subtheme 2: Experience of symptoms and behaviour

When talking about their experience of the illness, service users focused on the physical impact and caregivers focused on behavioural aspects. Service users reported the disturbing nature of hallucinations, predominantly auditory and visual.

‘.. I saw witches doing their private things. They were jumping over flames of fire. I saw them frying meat and jumping over the fire’ - Service user participant 8

They also reported unpleasant physical symptoms (some of which could be medication side effects), including feeling ‘heavy and confused’, dizziness, ‘feeling strained at the back of my head’, feeling a lack of control over their body, lack of concentration, difficulty sleeping, and disturbing dreams. One service user described how her inability to concentrate affected her ability to function:

‘I take a piece of paper [list of things to buy] each time I go to the shops. Even though I always have a piece of paper with me, I always wonder what to buy...and I feel so dizzy.’ – Service user participant 8

The majority of caregivers related their experience of the illness to their relative’s disorganised, violent or destructive behaviour (e.g. burning property, beating children, walking the streets aimlessly, refusing to bath).

‘We get scared and sometimes when she fights she can really hurt someone because she [is] very strong’ – Caregiver participant 14

2. Perceptions on the Course and Treatment of Illness

Subtheme 1: Knowledge of diagnosis

Knowledge of diagnosis was low among service users and caregivers. None were able to give the diagnosis that the service user had received in their clinic records. Three service users

believed that their illness could be cured completely and one did not believe that he was ill. Two service users and three caregivers specifically mentioned that when they went to health services they were given medication but that the illness was not explained to them.

‘They haven’t told me what kind [of illness] it is. She [service provider] says there are different mental illnesses, but they haven’t told me which type he has.’ – Caregiver participant 12

Subtheme 2: Experiences of pharmacological treatment

Overall knowledge on medication and side effects was low. None of the service users talked about their medication by name. The majority (eight) service users reported good medication adherence and an appreciation of its benefits. However five also noted challenges to adherence including being unable to get to the clinic to collect medication, forgetting an appointment, or forgetting to take medication due to symptoms. Five service users said that a family member helped them to be adherent. This is in line with caregiver reports that they helped ensure that the service user they cared for took their medication. By contrast, several caregivers described verbal and physical fighting over medication.

‘He tells me to take them [pills] myself and see what they do to me’. – Caregiver participant 17

Three service users expressed frustration linked to the different medications prescribed, one because her medication had been changed from what she was accustomed to and the second because of side effects.

‘They never give me the right medication, one day they give me these pills and the next time I come they give me different ones. When they give me different medication, I have headaches and pain in my body’. – Service user participant 7

Subtheme 3 Impact on emotional wellbeing

Service users and caregivers described how the illness had a significant negative impact on their emotional wellbeing. Two service users (both female) described how their illness caused them high levels of anxiety.

'Sometimes I feel like I'm running without knowing where I'm running to, as if something was chasing me' - Service user participant 8

Three service users mentioned having a short temper and one described his frustration at his inability to do things independently.

'I feel I'm inconveniencing the person who helps me if I'm unable to complete a certain task...I'm supposed to complete it on my own'.

Other emotional difficulties service users described included the loneliness of stays in hospital, and social isolation felt in everyday life. Caregivers described feelings of hurt and sadness caused by the service user's behaviour towards them (3 caregivers), fears of the service user's violent or aggressive behaviour (3 caregivers), embarrassment at their behaviour (e.g. lack of hygiene, 2 caregivers) and fears for their safety (e.g. when walking on the road, 3 caregivers). Six caregivers expressed a sense of loss in terms of how their lives could have been, had their family member not had this illness

'She [service user] could have been very successful, she used to love singing gospel and that's all that she ever wanted to do. I could also have been successful.' - Caregiver participant 14

Subtheme 4: Family conflict as an impact of the illness

Family conflict was described by both service users and caregivers. Two service users (both female) felt the illness had a negative impact on their intimate relationships. Two service users said their family believed that they acted deliberately to cause difficulty for the family. One service user then noted how this lack of understanding caused a worsening of his symptoms.

'They [family members] say 'You behave as if you are crazy and you are not'. When they say that, the voices attack me and become louder.' – Service user participant 2

One caregiver noted how the illness had caused 'chaos' for the whole family, and particularly had hurt the children of the service user.

'Yes, we are always stressed..., at night and in the morning you will find that we discipline him for all his mistakes. Then during the day...we shout at him'- Caregiver participant 17

3. Conceptualisation of and Support for Recovery

When talking about recovery and their ideas of a positive future, responses on recovery concepts identified from international literature (e.g. meaning and purpose) were limited. Several service users focused on meeting basic needs (e.g. food, clothing), indicative of the challenging conditions in which they live.

Subtheme 1: Healthy relationships

Three service users expressed their need to have positive relationships with those around them, including family members and service providers.

'I need to stop shouting at them [nurses, doctors, social workers] and start to be polite with them. And with my family so that there are not conflicts' - Service user participant

Subtheme 2: Importance of productive activity and work

The majority of service users highlighted the importance of productive activity in their lives, including household chores and gardening.

'When I'm feeling better, I'm able to do things for myself such as washing dishes and clothes. But when I'm unwell I can't do anything so my children help me.' - Service user participant 7

Seven service users highlighted the importance of work in their perception of a positive future.

Interviewer: When do you feel like your life has meaning and purpose?

Respondent : When I feel like what I was supposed to do for the day is completed.. Just like the job I used to do.... I was doing it with all my heart. Service user participant 2

Two service users noted that it was their lack of skills and education that was a challenge to finding employment. Three service users said their illness prevented them from working, noting the effect of symptoms and impairment in preventing them from performing work-related tasks.

Four caregivers believed the service user they cared for was unable to work due to being unable to do physically intense work, being aggressive, feeling tired, or due to their destructive behaviour and the unwillingness of employers to hire those with mental illness.

'She burns people's things, no she can't work. Others have hired her before thinking that she was normal but as time goes on they see that she is not well' – Caregiver participant 16

Subtheme 5: Support of traditional healers

Five service users said they had or would consult a traditional healer, either of their own accord, or at the direction of family. Three service users believed that the traditional healer had helped them understand or improve their symptoms. Two service users felt that they had not been effective, and three caregivers emphasized that they did not view traditional healers as effective.

'Modern doctors don't understand muti [traditional medicine] that people give you in your food. I think a traditional healer would help me understand the causes of this illness better.' – Service user participant 7

Three service users and one caregiver indicated that they thought both Western and traditional approaches could aid in their recovery.

'His [traditional healer] name is Mr. Peter, he helped and the pills helped me too. When I left Witrand [psychiatric hospital] I was feeling much better and I went to the traditional healer who helped me to recover fully.' – Service user Participant 6

Subtheme 6: Significance of religion

Service users and caregivers indicated that organised (Christian) religion and faith in God was key to coping with their disability and life circumstances. Several participants indicated that instead of worrying they put themselves 'in the hands of God'.

'I still see the man who attacked me ... but I've never opened a case against him, I just give everything to God.' – Service user participant 8

Caregivers gained comfort from their belief that God would protect the person they care for, and give them strength to fulfil their caring role.

'Each time the illness starts he just leave[s] the house and we do not know where he's staying, God is the one who will protect him.' – Caregiver participant 10

4. Experiences of Stigma and Discrimination

Subtheme 1: Experiences of health services

Three service users described good treatment at hospitals and clinics. Conversely, three service users described being treated badly by nurses. One service user described an experience of stigma related to his receiving a disability grant.

'They [nurses] said ... when we buy clothes we spend their money because it comes from their taxes. They said I should give them money because I get a grant and I'm arrogant.' – Service user participant 3

Subtheme 2: Treatment by family

Only one service user reported being treated with dignity and respect by family members. Seven service users reported various forms of ill treatment by family members, including verbal abuse, being refused food, being ignored when in need of help, and being prevented from leaving the home. Two caregivers provided evidence of verbal and physical abuse by other family members.

'There was a time when I went to my uncle to ask for help and he just shut the door in my face. I had been attacked with a knife, I only wanted help...' – Service user Participant 8

Subtheme 3: Experiences in the social environment

One service user said he was generally well treated and respected in his community, and four caregivers also described good treatment by neighbours. However four service users described various forms of ill treatment including being called 'crazy' or 'lunatic', being accused of

committing crimes, being refused help or financial loans, being refused service at shops, and being ridiculed.

'They just accuse me of things that I don't know about. They say that I kill people and they want to [take] revenge...they even call me a rapist'. – Service user participant 5

Community members also took advantage of service users' impairment. This included engaging the service user in work and not paying them, short-changing them at shops and sending them on unpaid errands. Two caregivers believed their female family members had been sexually abused.

5. Experiences Associated With Disability Grants

All service users interviewed were receiving disability grants from the South African Social Security Agency (SASSA) on the basis of their psychosocial disability. Two caregivers said that the grant was extremely helpful to their families, enabling them to eat even though no one was working. Grants were not always effectively managed, with three caregivers having to use grant money to pay off debts that the service user had incurred through buying meat, clothing or alcohol. Four service users reported managing the money from their grant themselves, and four said their caregiver managed the money. Three of these reported that their caregivers took advantage by spending money on themselves or withholding money. Conversely, one caregiver felt misunderstood due to being accused of mis-management of the grant.

'She says that the community is saying that I spend her money on my own things ... and that hurts me because I know that I'm not misusing her money' – Caregiver participant

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Despite this regular income, one service user articulated his desire to work and how the fear of losing his grant discouraged this.

'I wish I could go back to the shop and start working again. But they said that if I continue working then I won't get my pension money.' – Service user participant 5

6. Caregiver Burden

Significant burden emerged as a defining characteristic of the experience of caregivers. Several articulated a strong sense of responsibility to their family member with schizophrenia, exacerbated by the lack of involvement of other family members.

'Whenever she [gets] ill, everyone in the house backs off and the responsibility is left to me– Caregiver participant 14

One caregiver had suicidal thoughts related to her inability to cope with life as a caregiver.

7. Acceptability of Facilitated Group Approach

Four service users said they would be happy with a group facilitated by non-specialists. Two of these service users however highlighted the importance of these non-specialists being trained in the specifics of their mental illness. One service user said he would not join because he went to the hospital regularly and would get advice from the doctor. He did acknowledge that a reason for him to join would be to share his knowledge and experience with others. One other service user said they would not join without giving a reason. The remaining three service users did not respond to this question seemingly due to lack of understanding of the facilitated group format. Seven caregivers said they would join groups, however one said she did not have the time and one said the family member she cared for would not be able to participate due to difficulty with communicating.

Motivations for service users joining a group included doing something *'on the side'* to increase income, learning new skills, sharing experiences with people in a similar situation, keeping

busy, avoiding substance abuse, being reminded to take medication, and having positive social interactions.

'I would go to talk about my problems so that we can help each other'.-Service user participant 8

Caregivers motivations included gaining support and comforting one another, giving and gaining advice on how to cope with their caring role, sharing experiences and motivating each other, finding a release for their stress and emotions, and building friendships.

'If you talked to them [people in the group] about living with a mentally challenged patient then they could empathize with you. They would also share how they handled similar situations- Caregiver participant 17

Discussion

This study investigated the perceptions and experiences of service users with schizophrenia and their caregivers using interviews based on Kleinman's framework of explanatory models of illness (Kleinman, 1980). Participants in this study held little knowledge on biomedical aspects of the illness (symptoms, treatment) in line with previous research in the North West province which indicated low levels of knowledge of schizophrenia among service providers (Modiba et al., 2001) Traditional beliefs on causation were also common, in line with previous studies showing that attitudes, beliefs and experiences relating to schizophrenia are substantially different in South Africa from Western conceptualisations (Mbanga et al., 2002; Mosotho et al., 2011). Service users' conceptualisation of their recovery from the illness was characterised by high value placed on engagement in productive activities and the ability to work as reported previously in South Africa by service users and user advocates (Kleintjes et al., 2012; van Niekerk, 2009). Linked to the importance of work, the fact that some service users described their inability to meet their basic needs for survival (e.g. food) indicates the

pressing unmet need for a broad spectrum of supportive services. Despite the support net provided by disability grants, evidence from this study of the hardships for service users and their families caused by living in poverty, similar to those documented for service users with schizophrenia in other parts of South Africa (Swartz L., 2006), reaffirms the crucial need for psychosocial rehabilitation interventions to promote recovery and reintegration of service users into their community and into productive activity, including employment (Coetzee & Kemp, 1982; Lund et al., 2010; Petersen & Lund, 2011) . Support from traditional healers was important for recovery, in line with the South African context in which traditional healers provide significant psychosocial support for other conditions (Campbell-Hall et al., 2010). Religion or spirituality has been suggested to provide problem-solving strategies, a source of social support, the derivation of meaning, and improved self worth for those with severe mental illness (Ali beigi et al., 2011) and the reporting of the significance of religion for recovery and coping by service users and caregivers suggests this is the case in this context.

The study confirmed significant social disability, social isolation and stigma and discrimination experienced by service users reflective of the South African context in which schizophrenia is stigmatised significantly more than other mental disorders (Sorsdahl & Stein, 2010). Caregivers in this study also shouldered a heavy burden and both service users and caregivers were negatively affected by family conflict and lack of coping skills for dealing with the impact of the illness on their emotional well being and the functioning of their families.

Recommendations for psychosocial rehabilitation intervention

Data from this study provide direction regarding the design of a facilitated group psychosocial rehabilitation intervention as detailed in Table 2.

TABLE 2: Recommended elements of a contextually appropriate group psychosocial intervention for service users with schizophrenia and caregivers in the North West Province, South Africa.

Type of intervention	Need identified	Recommended strategy for addressing need
Service user intervention	<p>a. Orientation of facilitators to experiences and perspectives of service users</p> <p>b. Psycho-education on causes, symptoms, course</p> <p>c. Medication literacy and adherence support</p> <p>d. Reduce stress associated with family conflict and improve emotional well-being</p> <p>e. Tools for dealing with social isolation, experiences of stigma and discrimination</p> <p>f. Productive activities to help to reduce poverty and stress and improve role functioning</p>	<ul style="list-style-type: none"> • Training on the impact of poverty, stigma and discrimination and stress on service users. • Highlight importance of traditional and religious explanatory models of illness (EMI) and related coping strategies. • Highlight role of traditional healers and religious organisations in providing psychosocial support but emphasise adherence to medication. • Dedicate significant time in meetings for psycho-education adapted from evidence-based approaches. • Increase insight into individual nature of recovery and address expectations regarding cure. • Increase insight into coping strategies for symptoms. • Emphasise self-management and involvement in care. • Dedicate time in meetings for sharing accurate information on medication. • Involve a nurse or specialist if possible. • Address different types of medication, side effects and the fact that medication may change based on availability. • Provide information on role of family conflict in stress and relapse. • Skills building for managing anger and stress and dealing with conflict, coping skills for stress and anxiety. • Improve money management skills and communication around disability grants. • Skills building on problem management and healthy thinking. • Prioritise time for sharing of experiences on stigma/discrimination in meetings, encouraging peer support • Encourage group members to support each other outside of facilitated meetings. • Organise social activities in addition to group meetings. • Include information on importance of productive activity for recovery. • Link to skills development and employment opportunities. • Enable service users to contribute more effectively to household tasks.
Caregiver intervention	<p>g. Orientation of facilitators to experiences of caregivers</p> <p>h. Psycho-education on causes, symptoms, treatment, course, role of conflict</p> <p>i. Improve caregiver ability to create an environment supportive to recovery</p> <p>j. Reduce caregiver burden, improve emotional well-being</p>	<ul style="list-style-type: none"> • Training on impact of stress, burden, poverty, missed opportunities, lack of hope for future. • Increase empathy for service users, reduce fear. • Share strategies for coping with conflict. • Ensure opportunities for sharing of experiences and coping strategies. • Share information on accessing resources in community, caring for the caregiver. • Encourage environment of peer support • Incorporate sharing of information with extended family. • Build coping skills for dealing with stress and anxiety • Encourage participation of male caregivers.

1. Psychoeducation

Low levels of awareness amongst service users and caregivers of the diagnostic condition (even though awareness of the presence of a mental illness was common) highlights a need for the provision of clear and accurate information. Lack of knowledge limits service users' ability to participate in their care (Kleintjes et al., 2013a), a key aspect of recovery. The South African primary health care system is currently piloting a system that emphasises integrated chronic disease management, based on the Chronic Care Model (CCM) (Wagner et al., 2005) This emphasizes, *inter alia*, the need for informed and motivated service users who are able to take charge of managing their condition (Battersby et al., 2010) (Table 2b). Thus the proposed facilitated group intervention is timely and aligns with the development of the South African health system.

2. Adherence support

Low levels of knowledge on medication caused confusion for service users and difficulties with adherence. Similarly, service users had low levels of knowledge of medication side effects and some perceived possible side effects as symptoms of their illness (e.g. cognitive difficulties). Medication literacy for service users (and caregivers who have a key role in promoting adherence) is a clear need . In the South African context non-adherence may also be linked to services users' explanatory models of illness (Bhagwanjee, 2008) and lack of understanding of these on the part of service providers grounded in biomedical approaches. To effectively support adherence, facilitators of the proposed group intervention will need to encourage health promoting behaviours (e.g. adherence, knowing when to get help) alongside a traditional explanatory framework (Table 2a,h). This aligns with earlier work in South Africa indicating that service users with mental illness maintain traditional beliefs on the causation of their illness, whilst still seeking and valuing biomedical treatment for alleviating symptoms

(Lund, 1998). The current study also reinforces the need to move beyond the stereotype of the direct conflict between ‘Traditional African’ and ‘modern Western’ understandings of mental illness and recovery (Lund, 1998).

Coping Skills for Family Conflict and Emotional Wellbeing

Although some schizophrenia service users in South Africa see themselves as being valued and respected by caregivers despite the lack of community based supportive services (Manamela et al., 2003), in this study family conflict was evident as a source of stress for service users and caregivers. Their contrasting responses in some areas of this study suggest potential reasons for conflict, for example caregivers reported fighting over medication whereas service users reported significant caregiver support for adherence; service users expressed a desire to be productive whereas caregivers believed they were unable to do this. Clearly the experience of illness for service users and caregivers is exacerbated by living in poverty and similar to findings of a recent study of family therapy for schizophrenia in South Africa (Asmal et al., 2013), the proposed intervention will benefit from adaptation of conflict management strategies to specifically address poverty and its associated challenges.

. Stress and anxiety were important challenges to the emotional wellbeing of service users and caregivers in this study, and these too may be related to presence of conflict in the family. Beyond psychoeducation on schizophrenia, there is a need for increasing mental health literacy on other mental health problems, and building resilience and coping through sharing skills and practical strategies for managing stress and anxiety (Table 3d,k).

Coping Skills for Stigma And Discrimination

Data from the current study indicate that stigma and discrimination constitute a significant barrier to social integration of service users. Internalized stigma associated with this illness

may further compound the burden of psychosocial disability. This aligns with earlier work in the North West province showing schizophrenia service users to have particular needs in the areas of improving social networks and community integration (Modiba et al., 2001). Increasing knowledge and empathy amongst caregivers (Table 2i) may work towards reducing stigma and discrimination. It is equally important to equip service users with coping strategies for dealing positively with experiences of external stigma and discrimination (unlikely to change in the short term) (Table 2e) as well as internalised/self stigma. Finding effective ways for increasing awareness and understanding of mental illness in the wider community are clearly crucial but beyond the specific scope of the proposed intervention. However, there has been a call for greater prominence of service users in awareness raising and other advocacy initiatives in South Africa (Kleintjes, 2006) and facilitated groups may be an effective way to help mobilise service users towards advocacy and development of policy and services in which they currently have little participation (Kleintjes et al., 2010).

Income Generation and Productive Activity

Although disability grants provide a safety net from absolute poverty for service users and their families, data from this study also indicate they can be a source of conflict. Improving money management and communication skills is indicated (Table 2d). Many service users in this study emphasized that social integration in the form of working and earning an income would be the cornerstone of recovery.. In the wider context of poverty, unemployment, and multiple dependents on disability grants, a significant motivator for participation in groups may be opportunities for income generation to add to income derived from grants (Table 2f) as has been the case in user-led groups in other African countries which have incorporated strategies for sustainable livelihoods such as group savings schemes and income generating cooperatives (Kleintjes et al., 2013b). Data from this study also indicate the importance of productive

activity in the household other than work and income generation. Improving service users' contribution to household tasks may help to boost self esteem, with the additional benefit of helping to reduce burden on caregivers (Table 2f).

Addressing Caregiver Burden

The frequency of reporting in this study of significant caregiver burden suggests a need for a separate intervention to support family/caregivers. Families who are best equipped to care for a person with schizophrenia are educated on the illness and engaged in seeking help (Rose, 1996). Access to information on the supportive resources available in the community acts as a buffer to the burden of care (Caqueo-Urizar & Gutierrez-Maldonado, 2006). The proposed intervention should therefore incorporate these aspects as well as enabling caregivers themselves to share their own coping strategies with each other (Table 2k). In this study, all caregivers interviewed were female, corresponding to the global picture of care giving (Esplen, 2009). Low levels of perceived support from other family members have been associated with higher caregiver burden (Biegel et al., 1994) and for countries such as South Africa where the social welfare system (e.g. sheltered living) is inadequate, it may be beneficial to focus on ways of strengthening extended family relations (Ohaeri, 2001), increasing the role of men in care giving (Table 2k).

Promoting Acceptability

There is some evidence that a facilitated group approach may be acceptable to service users and caregivers in this study – only two people said they would not join if accessible groups were set up. There was an expressed need for group facilitators to have specific training on schizophrenia and a particular sensitivity to the impacts psychosocial disability has on service users' lives. This highlights the need for specifically designed training for group facilitators. This training should also incorporate orientation towards acceptance of service users'

explanatory models of illness. In this study service users and caregivers linked their experiences of illness/disability to stress and poverty and empathy for this reality will be key to promoting acceptance. Religion as a coping strategy was commonly reported in this study. Making provision for understanding and supporting religion and spirituality (Ali beigi et al., 2011) rather than assuming this is a result of psychopathology (Reiland, 2008) may further increase the acceptability of the proposed intervention (See Table 2a).

Both caregivers and service users in this study indicated that mutual support and sharing experiences would be an important motivator for participating in groups. This grounding in peer support as a facilitator of recovery has been the basis of user-led organisations that have developed elsewhere in Africa (Kleintjes et al., 2013b). While a user-led group approach is likely to be the most acceptable form of intervention, service users in this study were disempowered by their lack of knowledge on their illness, lack of education, and their lack of access to basic services. A facilitated group approach may be a positive first step in moving towards service users' self organisation and advocacy. The groups would also benefit from linking with The South African Mental Health Advocacy Movement to develop over time in line with this model of peer-led groups.

Limitations

This study was limited in having a relatively small sample (comprised of two sub-groups, with differing views and experiences) and in following a convenience sampling strategy. This may have introduced homogeneity in the life circumstances and experiences of participants. A response bias may also have been introduced due to the setting of interviews in a health facility. The study was limited by difficulties in gaining responses to all interview questions due to the level of functioning of some service users. The clinical training of the interviewers and their

understanding of the symptomatology of schizophrenia was a strategy employed to ensure the best data possible was gained. However this could also have introduced a limitation in terms of reducing their perspective and sensitivity to salient cultural issues relevant to participants understanding of mental illness and recovery. Similarly the one interviewer's position as a traditional healer may also have introduced a bias towards this perspective. Both interviewers received specific training on the interview schedule aiming to reduce these possible sources of bias. Other limitations include the potential for researcher biases in this type of qualitative research analysis.

Conclusion

This study has highlighted the multiple challenges faced by service users with schizophrenia and their caregivers in South Africa, encompassing not only the experience of disability but also the impact of high levels of poverty. The study has identified potential elements of a contextually and culturally appropriate group psychosocial intervention, linked to the perceptions and experiences of service users with schizophrenia and their caregivers in the Dr Kenneth Kaunda District, North West province.

Declaration of Interest

The authors report that they have no conflict of interest.

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**Chapter 4: Intervention materials for the
psychosocial rehabilitation intervention:
Facilitator training manual and Facilitator
Guide**

PRIME Psychosocial Rehabilitation (PSR) Programme

Trainer's Manual

**2014
PRIME
edition**



Name



The authors thank Basic Needs for adaptations from their 'Mental Health Manual for Training Community Health Workers' and the University of KwaZuluNatal for adaptations from their 'Psychosocial Rehabilitation Programme Manual for Community Rehabilitation Centres'.

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» PSR facilitators training workshop: Day 1

PURPOSE: The purpose of Day 1 is to create a safe environment for learning and to create a productive group learning environment for participants. By the end of Day 1, participants should be clear on their role within the PSR programme and have begun to gain information and skills to enable them to form and run groups.

The activities in this training programme are designed to give participants a chance to share experiences and learn from each other. This training follows an adult learning approach – where people learn best through being able to apply new concepts to what they already know and to their life experience.

Some of the topics discussed in this training may be sensitive, for example if people have a relative or friend who has a mental illness or if they have a mental illness themselves. Encourage participants to share their experience but clarify that no one should feel pressurised to share anything they are not comfortable with. Also make sure you have someone you can refer participants to for further support should they need it. It is important that they maintain their own mental health.

Sit together with your co-trainer/s, read through the programme and decide who will lead the various activities of Day 1. Discuss how you will support one another today.

Materials checklist for Day 1

Materials	Notes	Checked
PSR Trainer's manual	Bring your own copy	
PSR Facilitator Guide	Bring enough copies for the number of participants	
Attendance register	Use usual register	
Flipchart and pens	Check with venue	
Prepared flipcharts to put up	Check in each session what needs to be prepared in advance	
Handouts	Prepare photocopies of handouts for the Day (see session outlines)	
Prestik	For hanging flipcharts	
Extra pens	For pre-training evaluation	

1.1 Preparation – Self & environment

30 mins

ACTIVITY

- Prepare yourself and check in with your co-trainer.
- Prepare the venue.
- Greet everyone on arrival.

AIM

- You feel prepared.
- Everyone feels welcomed.

MATERIALS

- All the materials listed in the materials checklist.

TIME MANAGEMENT

- Self- and room preparation – 30 mins.

INSTRUCTIONS

1. First check in with your co-trainer to go through the main activities of the day.
2. Decide who will lead each activity if not decided previously. Write this in the relevant column in the programme.
3. Lay out name tags, marker pens, programmes and attendance register on your table.
4. Arrange seating so that everyone can see you.
5. Welcome participants as they arrive and ask them to write their name tags and complete the attendance register.

1.2 Welcome & group introductions

15 mins

ACTIVITY

- Welcome everyone to the training.

AIM

- Create a safe environment for learning.
- Encourage participants to feel comfortable sharing with the group.

TIME MANAGEMENT

- Welcome – 1 minute
- Introductions – 10-15 minutes (depending on size of group)

INSTRUCTIONS

1. Thank everyone for coming.
2. Introduce yourselves by giving your name and your role in the PSR training programme.
3. Allow participants to introduce themselves by saying their name, where they work and one interesting fact about themselves.
4. Provide an example for how to respond. For example; my name is Letta, I work at the Mental Health Society and I have a twin sister.
5. Acknowledge each contribution and move to the next person.

1.3 Addressing expectations & concerns

15 mins

ACTIVITY

- Group discussion

AIM

- Allow for safe expression and normalization of anxieties.
- Create a safe environment for learning.

MATERIALS

- Flipchart, koki pens and Prestik.

TIME MANAGEMENT

- 15 minutes

INSTRUCTIONS

1. Invite the group to share their expectations and any concerns related to this training workshop.
2. As the group shares, acknowledge each contribution and keep on asking open-ended questions to ensure participation.
3. Normalise any concerns expressed by asking if anyone else feel the same as XXX, or ask whether anyone else in the group has similar concerns.
4. Give co-trainer/s an opportunity to express their expectations from the group (e.g. active participation).
5. Write the contributions on the flipchart and hang them up on the wall once completed.

1.4 Group norms

10 mins

ACTIVITY

- Group discussion

AIM

- Set out standards of behaviour for effective group work
- Encourage sharing of experiences and participation.

MATERIALS

- Flipchart, koki pens and Prestik

TIME MANAGEMENT

- 10 minutes

INSTRUCTIONS

1. Invite the group to share ideas for some 'ground rules' or norms that will help them work together effectively.
2. Ensure that the following have been mentioned:
 - a. Everyone respects each other
 - b. Everyone listens to one another
 - c. One person speaks at a time
 - d. Everyone has a chance to speak
 - e. Time management and sticking to the topic at hand
 - f. Cell phones OFF
 - g. Respect confidentiality.
3. Write the 'group norms' on the flipchart and hang them up on the wall for the duration of the workshop.
4. Decide how the group wants to begin and end each day (some groups like to sing or pray).

1.5 Introduction to the programme

60 mins

ACTIVITY

- Trainer presentation
- Group discussion
- Review of handout

AIM

- Understand aims of PSR programme
- Understand Facilitator role
- Awareness of PSR Facilitator Guide

MATERIALS

- Handout 1, Flipchart, koki pens and Prestik

TIME MANAGEMENT

- See individual sections below

INSTRUCTIONS

Part 1: Orientation to the Psychosocial Rehabilitation Programme (15 mins)

1. Ask some participants to share how they became involved in this programme.
2. Highlight that people have come from different backgrounds and everyone has something unique to bring.
3. Give a short explanation of the PSR programme:
 - a. It is a programme for supporting people with schizophrenia to function in their community
 - b. Participants will facilitate support groups for people with schizophrenia and separate support groups for caregivers
 - c. For this reason, they are known as 'PSR Facilitators' in the programme
 - d. In the programme, PSR Facilitators will set up and run 12 support group sessions for people with schizophrenia, and 5 sessions for caregivers, over a period of 3 months.
 - e. Emphasize that it is not just the support groups that take time. Planning the groups, finding people in the community and getting them to come to the groups also takes time and effort. There is a plan for how to do this and this is covered in the training.
4. If possible, at this point introduce someone who has participated in the groups previously, to share their experiences of how the group benefited them. Give a chance for participants to ask questions.

Part 2: PSR Facilitators and Supervisors Roles (45 mins)

1. Give out Handout 1 that covers Facilitators' and Supervisors' roles. Go through each of the roles and steps that enable the formation and running of the groups. Explain the need for confidentiality in the group and hand out copies of the forms required. Also explain the importance of the attendance list and hand out an example.
2. Ask for any question or clarifications. Encourage participants to keep this Handout as a reminder of their work process for the next few weeks. **(15 mins)**
3. Use the handout to introduce the process of supervision:
 - a. Ask participants what they think the purpose of supervision would be in this programme
 - b. Ask what the role of the supervisor would be
 - c. Summarize the role of the supervisor in providing supportive supervision**(15 mins)**
4. Explain that the training over the next 3 days will enable Facilitators and Supervisors to fulfill their roles. Give a brief outline of the training programme:
 - a. Use the programme outlines for Day 1 – 3 and give a synopsis of the topics to be covered.
5. Lead a discussion on some of the principles for effectively running groups. Ask participants for their experience and ideas on facilitating groups in the past. How do they make group members feel comfortable? How do they build trust and encourage participation. Compile a list on the flipchart. Give out Handout 2 and go through the points. Ask for participants ideas on these Top Tips.
6. Next hand out to each participant their copy of the Facilitator Guide.
7. Explain that this document contains outlines that will assist them in running PSR support groups. **(5 mins)**
8. If there are people in the group who have already worked on this programme, ask them to share some of their experiences **(10 mins)**

Handout 1

PSR Facilitators and Supervisors Roles

1 PSYCHOSOCIAL REHAB PROGRAMME INITIATION

Health Promoter arranges initial meeting with facility manager, nurses, community health workers, auxiliary social workers.

Outputs:

- Agree on date for start of programme (allowing time for initial meeting and tracing of users)
- Agree with facility manager on specified day for all schizophrenia patients to come to collect their medication and meet with Health Promoter.
- Health Promoter allocates date, time for each group session. Books clinic space as needed, creates programme with dates and times.

2 SERVICE USER REFERRAL

Nurse informs patients about group at scheduled appointments, schedules following month's appointment for all on same day, introduces the support group, refers to Health Promoter and reminds about following months medication collection. Health Promoter collects contact details, first language information, gives date for first meeting.

Output:

- Appointments for service users arranged for agreed day in following month
- Nurse keeps list of service users informed and communicates with Health Promoter

3 INITIAL MEETING WITH GROUP MEMBERS & IDENTIFICATION OF NON-ATTENDERS

Health Promoter and auxiliary social worker conduct initial meeting, introducing programme, aims and benefits, collecting service user names, addresses and contact number or contact for a caregiver. Checks list of attendees at initial meeting with clinic records of patients with diagnosis of schizophrenia, compiles list of those needing to be traced.

Outputs:

- List of service users who did attend initial meeting for CHWs to follow up with caregivers and invite to attend caregiver group
- List of service users who did not attend initial meeting for CHWs to trace (and contact caregivers at the same time)

4 SERVICE USER AND CAREGIVER TRACING & MOBILIZATION

Health Promoter informs CHWs of service users and caregivers to be traced and invited to attend group

Output:

- CHWs inform service users and caregivers of the programme, give information on the programme and written invitation as well as programme with dates and times for sessions.

5 ALLOCATION TO SERVICE USER & CAREGIVER GROUPS

Output:

- Health Promoter develops attendance list based on those who have committed, and first languages of service users, allocates to groups if more than 10 participants, finalises programme/s accordingly.

6 GROUP COMMENCEMENT & IMPLEMENTATION

Health promoter/Auxiliary social worker conduct group sessions as per programme. CHW follows up non-attenders (home visits).

Outputs:

- Attendance registers for each session
- Confidentiality agreements signed at beginning of first session
- Copies of any referral forms retained

7 SUPERVISION

Supervisor attends first two sessions in programme, providing support and feedback. Supervisor and PSR Facilitator meet once a week for the first month and then twice a month for remainder of programme (face to face supervision meetings). PSR Facilitator 'buddies' provide feedback and support to each other following each session

Outputs:

- Peer to Peer supportive supervision form for each session

Handout 2

Top Tips For Facilitating PSR Support Groups

- Be prepared. Review the topics and questions in the Session guidelines.
- As people begin arriving, be sure to make eye contact and say hello, greeting them by name.
- Start the meeting on time if possible to encourage other members to be prompt.
- Encourage members to listen to each other.
- Encourage members to offer support to one another. For example, you could say “Catherine, what can you say to Bonang that might help?”
- Encourage members to talk about themselves.
- Encourage an atmosphere where members feel comfortable talking about themselves and their experiences – this gives others the chance to give support, ideas and help.
- Emphasize the importance of confidentiality. So members feel safe to talk about their experiences and problems
- Help members solve problems. This is not the facilitator’s responsibility, but through discussion and sharing of experiences, members may be able to help each other solve problems they face.
- Try to help members focus on the positive aspects of their lives and how they can improve their lives.
- Don’t let one member dominate and use the meeting as a chance to air all their complaints and problems. Some people naturally like talking, others have to be brought out of their ‘shells’.
- Encourage outside contact among members. Members can offer support to each other outside of meetings. Members can share cell phone numbers and can contact and support each other outside of the meetings.

1.6 Introduction to mental illnesses

25 mins

ACTIVITY

- Group discussion and sharing of experience

AIM

- Introduce participants to mental illnesses

TIME MANAGEMENT

- Discussion – 10 mins
- Sharing experiences – 15 mins

INSTRUCTIONS

1. Use the following questions to guide a discussion around mental illness:
 - a. What are mental illnesses?
 - b. What causes mental illnesses?
2. Write responses on a flipchart.
3. Ask whether anyone has any experiences to share about working or living with someone with a mental illness. You could also share your own personal experience.
4. Some people are more vulnerable to mental illness than others. Ask the group to brainstorm what could make people vulnerable to mental illness. For example, being at risk of violence and trauma could make people vulnerable.
5. Summarise the activity by covering the key information below.

DISCUSSION

- Common mental illnesses are problems such as excessive fear and worry (anxiety) or unusually sad mood (depression)
- More severe behavioural problems can involve suspiciousness, violence, agitation and other unusual behaviours or experiences.

Most mental illnesses are caused by a combination of factors:

- Stressful life events – e.g. family conflicts, unemployment, death of a loved one, money problems, violence
- Biological factors - genetics, brain injury, and chemical imbalance in the brain. Mental illnesses can run in families (genetic factors) but this is not the only factor and family members need not be 'blamed'
- Traumatic life experiences during childhood e.g. abuse, neglect, death of parents
- Poverty can place a person at risk of mental illness because of the stresses of living with poor housing and low income.
- Drug abuse can also make a person more vulnerable to mental illness.

1.7 What is schizophrenia?

35 mins

ACTIVITY

- Analysis of scenario

AIM

- Familiarise participants with schizophrenia as an illness

MATERIALS

- Handout 3

TIME MANAGEMENT

- Analysis of scenario – 20 mins
- Discussion – 15 mins

INSTRUCTIONS

1. Ask participants whether they have worked with a client with schizophrenia. Ask anyone who has to share their experience and what symptoms the client had.
2. Explain that:
 - a. People with schizophrenia are said to have psychosis, which is a combination of hallucinations and delusions.
3. Ask whether people know what hallucinations and delusions are. After getting some ideas – give the definitions below:
 - Hallucinations** - Hearing voices/seeing things that are not there
 - Delusions** - False beliefs e.g. thinking others are trying to harm them
4. Share that other signs of schizophrenia include:
 - a. Strange behaviours e.g. talking to him/herself
 - b. Inappropriate emotions e.g. laughing at something sad
 - c. Loss of social skills
 - d. Restlessness, walking up and down
 - e. Aggression.
5. Ask participants if they have recognized these symptoms or behaviours in people they know or in their community. Allow time for sharing of experiences.
6. Divide the group into smaller groups/pairs.
7. Give them Handout 3 which has a scenario.
8. After reading the scenario, groups need to identify signs and symptoms of schizophrenia.
9. Trainers should spend time with each group, helping facilitate their discussion of symptoms. Ensure they understand the delusions and hallucinations in the scenario.
10. Ask each group to share their findings. Summarize and give the information points below.

DISCUSSION

- Schizophrenia generally has its onset before the age of 30 years
- Both men and women are affected
- Hallucinations and delusions are common symptoms of schizophrenia
- People with schizophrenia may also commonly suffer from depression due to the way the illness impacts on their life and they can be at risk for suicide
- They may abuse alcohol or drugs as a way of coping
- There are effective treatments that can reduce the symptoms but they cannot be 'cured' as such.
- People often have the misconceptions that people with schizophrenia are always dangerous or criminals but this is not the case

Handout 3

Schizophrenia Scenario

Dipuo is a 23 year old student who started locking himself in his room. He used to be a good student but failed his last exams. His mother says that his room is dirty and he refuses to open the curtains or windows. She tells you that Dipuo often spends hours staring into space and sometimes mutters to himself as if he were talking to an imaginary person. He was forced to come to the clinic by his parents, they are unable to get a good nights' sleep as Dipuo walks around the house at night, and he refuses to bath. At first he refused to talk to the nurse. After a while he admitted that he knew his neighbours were plotting to kill him, he said "they have sent spirits to take over my mind". He said he could hear his neighbours talk about him and say nasty things outside his door, and that he received a message from the radio warning him to be careful. He believes that he has been bewitched, and did not see why he should go to the clinic since he was not ill.

1.8 Understanding the experience of people

with schizophrenia

30 mins

ACTIVITY

- Review of examples of hallucinations and delusions
- Discussion in pairs
- NOTE: If there is a service user with schizophrenia who has been part of the programme who could come and share their experiences, this will be a powerful experience for Facilitators and Supervisors.

AIM

- Build empathy for support group members

MATERIALS

- Handout 4
- Flipchart with questions for discussion in pairs (see below)

TIME MANAGEMENT

- Review of Handout – 5 mins
- Discussion in pairs – 15 mins
- Report back – 10 mins

INSTRUCTIONS

1. Pass out the copies of Handout 4. Ask participants to individually spend several minutes thinking about what it would feel like to experience these symptoms.
2. Next, ask participants to pair up and together discuss these questions. Put up the flipchart you prepared:
 - a. What would it feel like to have schizophrenia?
 - b. How would people treat me?
3. Bring the group back together and ask some participants to share their discussions.

TRAINER HIGHLIGHT: The aim of this activity is to help participants build empathy. We all need to reflect on how we can see past the label of 'mental illness' and see people as valuable, capable individuals, rather than just as 'mentally ill'.

DISCUSSION

- People with schizophrenia may retreat from social contact and lose meaningful relationships with friends and family
- They may stop being involved in their community (e.g. churches, community groups)
- Family, neighbours and community may not understand mental illness and may treat them poorly because of their strange behaviour.

Handout 4

What Does It Feel Like To Have Schizophrenia?

Remember: To the person with schizophrenia, hallucinations and delusions are real, and can be extremely disturbing

Think about how it would feel to have delusions

- Feeling that people are talking about you or looking at you
- Feeling that you are being watched, followed, and spied on (e.g. tracking devices, hidden cameras)
- Strong belief that someone is trying to poison your food
- Strong belief that people can read your mind or control your thoughts
- Strong belief your thoughts are being broadcast over the radio or TV
- Strong belief that random events have a special meaning to you. E.g. a newspaper headline has a message for you
- Thinking that you are Jesus, God or a prophet

Think about how it feels to have hallucinations

- Most people with schizophrenia hear voices – sometimes in their head or sometimes an actual voice. Sometimes they come from nowhere, but sometimes they come from real people who don't actually say anything.
- When people hear voices inside their heads, the voices can talk to each other, talk to themselves, or comment on the person's actions. Most of the time the voices say negative things. The voices may be insulting or abusive and sometimes command people to commit violent/destructive acts or suicide.

1.9 Understanding the experience of caregivers 30 mins

ACTIVITY

- Sharing of family experiences
- Reflection on the experience of caregiving

AIM

- Participants understand the challenges faced by family/caregivers and the reasons they too need support

TIME MANAGEMENT

- Activity 1 or 2 – 30 mins (note there are two alternative activities depending on whether you have a family member who is willing to come and speak at the training)

INSTRUCTIONS

1. Ask participants why they think it is important to involve caregivers in the programme.
2. Introduce the activity by saying that in South Africa people with schizophrenia are most commonly cared for by their families because there may not be other suitable accommodation options like 'half way houses'. A family is greatly affected by having a member or relative with schizophrenia. The symptoms of their illness can result in erratic or difficult behaviours, depletion of resources (e.g. because they are not working) and strained relationships.

Activity 1: Sharing Family Stories

If you are able to arrange this in advance, it can be powerful to have a family member of a person with schizophrenia come to share their experiences. After about 15 minutes, open up the floor for questions from participants. Ensure that all participants show respect and understanding for the family member's experience. Thank the family member for their input.

Activity 2: 'Your hopes on a card'

1. Hand out to each participant a piece of paper or card.
2. Explain that each person should write on their card one of their hopes for the future. For example 'I hope to build a house' or 'I hope to get married'. They should then fold the cards up, and exchange them with the person next to them.
3. Next ask everyone in the group to imagine that they are a person who is the primary caregiver for a person with schizophrenia. This may mean that they have to:
 - a. Help the person remember to take medication
Accompany the person to the clinic, hospital or anywhere else they want to go
 - b. Manage the person's money
 - c. Ensure there is food and other essentials
 - d. Cook, clean etc for the person
 - e. Help them to maintain personal hygiene
 - f. Help look after their children if they have any

4. Now go round the group asking each person to share the 'hope' on their card, still imagining they are a caregiver for a person with schizophrenia. Would they be able to achieve this hope/dream? What challenges would they face? How would they feel?
5. Ask each person to now write on the back of the card they have, one of the 'fears' they would have as a caregiver of a person with schizophrenia. They should pass the cards around again, and then each person has a chance to share the 'fear' written on their card.
6. End the activity with the discussion points below.
7. Ask for two participants to volunteer to prepare a role play for the activity after the lunch break. See activity in Section 1.10 for guidance.

DISCUSSION

- Families of people with schizophrenia may feel shock, denial, anger, loss and then eventually acceptance of the illness.
- The family is often socially and economically disadvantaged. This is particularly true if the caregiver has to stay at home and cannot work due to their responsibility in taking care of the person.
- Caregivers needs, hopes and dreams are often secondary to the day to day challenges of caring for the person
- These caregivers may also have others (e.g. small children) to care for
- Caregiving for a person with schizophrenia can be emotionally draining due to the way the illness affects the persons behaviour
- Caregivers also have to deal with high levels of stress as well as their own feelings of loss and sadness due to the challenges in their lives.

1.10 Schizophrenia & the family – the effect of conflict

30 mins

ACTIVITY

- Role play and discussion
- Sharing of experiences in pairs

AIM

- Participants know the role of family conflict in increasing risk of relapse and caregiver burden
- Participants have reflected on some ways families can reduce conflicts

TIME MANAGEMENT

- Activity 1 – 15 mins
- Activity 2 – 15 mins

INSTRUCTIONS

Activity 1: Role play – family conflict

1. Ask the volunteers to act out the role plays below that they prepared.
2. The role play should take about 5 minutes. After this, use the discussion questions below to guide a discussion on family conflict.

» Role Play: Family Conflict

DINEO	Is there some food for this evening. I am so hungry and I need to eat before I take my tablets.
MALE RELATIVE	My wife is not here today, why have you not cooked food? We come home from working all day and there is nothing for us. What have you been doing all day? Sitting under a tree? You are useless. What kind of a woman are you that you do not cook for the men who work?
DINEO	I'm sorry but there was no food in the house today and I could not take a taxi to go to try and buy food.
MALE RELATIVE	I don't care about your excuses. I think you are not sick at all you are just faking it, you are acting like that deliberately so that you can have others do everything for you.
DINEO	That is not true, I am sick, and I am trying my best to do what I can. If my aunt was here to help me we could have gone together and bought food, and she would help me to make it.
MALE RELATIVE	More excuses. I should just throw you out on the street, then you would see what a hard life is like. That would make things a lot easier for us here anyway. You better watch out or I might just do that.
DINEO	[very upset] Please....I'm sorry. I will try harder.

Discussion Questions:

- What do you understand by the term 'family conflict'?
- How could family conflict affect a person with schizophrenia?
- How could family conflict affect caregivers?

DISCUSSION

- Family conflict causes high levels of stress for caregivers, and can increase the risk that the person's illness will worsen
 - Family conflict can be caused by the difficult behaviour of the person with schizophrenia
 - But family members may also treat the person with schizophrenia very badly.
-

INSTRUCTIONS**Activity 2: Working on Family Conflict**

1. Ask participants to pair up, and share their experience of conflict within their own family. How have they dealt with it? What support could they give to caregivers in dealing with family conflict? Remind everyone to share only what they feel comfortable with.
2. After 15 mins let each pair have a chance to feedback their strategies for dealing with conflict and ideas for helping caregivers.

DISCUSSION

- Caregivers and family can encourage treatment adherence to get the person's symptoms under control, which may lead to less difficult behaviour
- Family members need knowledge on the illness so they can be supportive.
- Caregivers can also share their ways of coping with family conflicts in support group meetings
- If needed, the family can involve a social worker or other professionals, as well as trusted friends or extended family members in helping them to resolve the conflict
- Family members and the person with schizophrenia themselves should always avoid resorting to violence and all should treat each other with respect and dignity

1.11 Understanding stigma & discrimination

30 mins

ACTIVITY

- Presentation of definitions
- Brainstorm and discussion

AIM

- Enable participants to understand stigma and discrimination

TIME MANAGEMENT

- Brainstorm – 15 mins
- Discussion – 15 mins

INSTRUCTIONS

1. Ask a participant to read out the following quotes...

Stigma is: '... a mark of shame, disgrace or disapproval, which results in an individual being shunned or rejected by others.'

Discrimination is the unfair treatment towards those who are stigmatised, whereby they are treated less favourably than those who are not stigmatised. For example, people may be discriminated against because of their race, age or gender (or because of having a mental illness).

2. Lead a discussion about how these concepts are used in SeTswana. What are the literal translations? What words are used to describe the experience of stigma and discrimination?
3. Ask a participant to read the following story:

Bonang is a 45 year old mother of two boys. She has been diagnosed with schizophrenia for the last 10 years. Her husband passed away and she is not working. She used to work as a domestic worker but when she had a relapse and had to spend time in hospital her employer told her not to come back to work. Now that her boys are older they sometimes call her a 'mad old woman' and her neighbours avoid her in the street. She is taking her medication but sometimes she thinks this illness is her own fault that she brought it on herself because of the fight she had with her late husband just before he died. They didn't have the opportunity to reconcile and she thinks he is punishing her from the world beyond.

4. Explain that there are several types of stigma in this story.
5. Ask participants if they can identify these. They may easily identify stigma from the family members and the neighbours. But the less well known form of stigma is self-stigma or internal stigma – stigma the person with the illness feels towards them self.
6. Use the points below to round off the activity.

DISCUSSION

- Not knowing the facts about mental illness sometimes makes people afraid of those with mental illnesses. People often think that those with mental illness are acting deliberately
- A person with mental illness may be rejected by friends, relatives, neighbours and employers.
- Stigma also affects the family and caregivers and may lead to isolation and humiliation
- Self (internal) stigma can lead to low self esteem, feelings of worthlessness and withdrawal from social/community life
- Because of the labelling and shame associated with schizophrenia, self stigma may be especially strong.

1.12 Management of schizophrenia

30 mins

ACTIVITY

- Description of the basics of the SA Mental Health Care Act
- Brainstorm on the care of a person with schizophrenia

AIM

- Participants know the different service providers involved in care for those with schizophrenia

MATERIALS

- Handout 5

TIME MANAGEMENT

- Brainstorm – 20 mins
- Review of Handout – 10 mins

INSTRUCTIONS

1. Explain that the South African Mental Health Care Act of 2002 outlines what care people with severe mental illness should get:
 - a. A Person with severe mental illness who is a danger to themselves or others can be hospitalised (voluntarily or involuntarily) where they will be observed for 72 hours and receive treatment from a psychiatrist
 - b. Once stabilised they are entitled to leave hospital and continue to receive medication from their clinic or doctor
 - c. They are entitled to rehabilitation to integrate them into their communities after leaving hospital
 - d. Mental health review boards exist in all the provinces. A caregiver or service user themselves can appeal to this board if they feel they do not need to be hospitalized or have been hospitalized without good reason
 - e. Ask for any questions or clarifications on the Mental Health Care Act.
2. Explain that people with schizophrenia and other severe mental illnesses are entitled to a disability grant based on their psychiatric disability. This is a recognition by the government that the illness makes it difficult for them to work and function in their community. These grants are administered by SASSA and often the Mental Health Society administers the grant if there is a service users who mismanages their grant, or whose family do so.

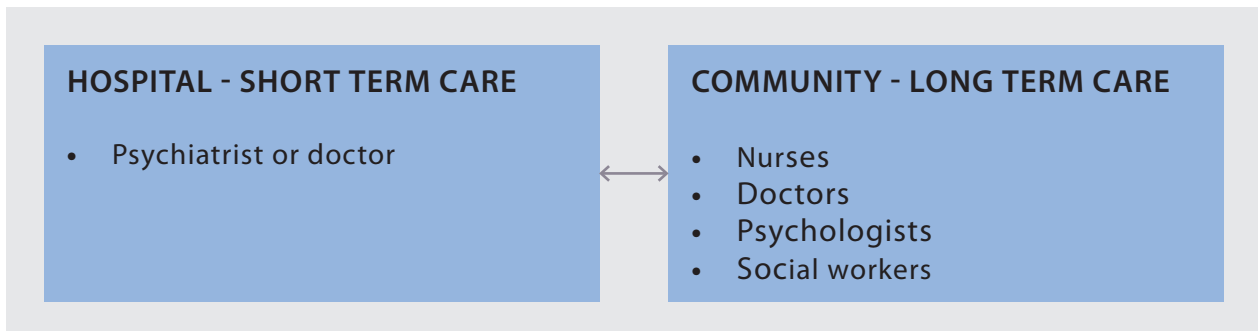
3. Ask for representatives from the Mental Health Society to share their experiences on administration of grants.
4. Next ask a participant to read out this story to the whole group:

Michael is a 27 year old factory worker. At a point in time his family started to notice changes in him. He stopped going to work and would walk the streets all day, he would talk loudly to himself and point to things that no one else could see. Eventually he lost his job and his family were called late one evening to go to the police station as Michael had been arrested, he had tried to set fire to a neighbour's shack. After being arrested Michael was admitted to hospital, the police said this was what they had to do because of the Mental Health Act.

5. Ask the participants to divide into small groups/pairs.
6. Using the questions below, groups should brainstorm:
 - a. What care does Michael need in the short term?
 - b. What care would Michael need in the long term?
7. Bring the groups together to report back on their brainstorm. Ask a volunteer from each group to share what they discussed.
8. Hand out to participants Handout 5 - use the information to add to the groups discussions.

Handout 5

Service Providers Involved in Care for Schizophrenia



Psychiatrist provides diagnosis and medication. If no psychiatrist available, doctor provides diagnosis and medication.

Psychologists provide counselling and support

Nurses do monthly checkups and provide ongoing medication

Doctors check that medication is working and change medication if there are side effects

Social workers help with accessing disability grants and provide support to the patient and family

Occupational therapists can help with rehabilitation and recovery

1.13 Closure

15 mins

ACTIVITY

- Summary and time for questions/clarifications

AIM

- Participants are clear on key learning points from Day 1 training.

TIME MANAGEMENT

- 15 minutes for closure and questions

INSTRUCTIONS

1. Thank participants for their energy and participation today.
2. Summarise the key learnings for the day:
 - a. Schizophrenia can affect anyone and is difficult for individuals and families to cope with
 - b. Stigma and discrimination and poverty add to the challenge
 - c. PSR Facilitators and Supervisors role is to help people with schizophrenia to function better in their community.
3. Ask if anyone has any questions or anything to clarify from the Day 1 training.
4. Remind participants of the start time for Day 2 training and to bring their copy of the PSR Facilitator Guide.
5. End the Day's training in the way the group discussed in the first session e.g. with a song or prayer.

Trainers reflection tool: Day 1

Some questions for today's reflection ...

What worked?

What did not go so well?

What aspect of training do we think we need to support tomorrow?

Who are you worried about in the group? What can you do to support this participant?

What do you appreciate about your co-facilitator?

What assistance do you need from him or her tomorrow?

» PSR facilitators training workshop: Day 2

PURPOSE: The purpose of Day 2 is to begin to build participants' skills for working with people with schizophrenia. The format is similar to Day 1 - there is a lot of information that can be shared by the trainer (e.g. in summary discussions at the end of an activity). It is important to get participants to share their ideas and experiences and to build on what they learned in Day 1.

Sit together with your co-trainer, read through the programme and decide who will lead the various activities of Day 2. Discuss how you will support one another today and incorporate what you learned and experienced in Day 1.

Materials checklist for Day 2

Materials	Notes	Checked
PSR Trainer's manual	Bring your own copy	
Attendance register	Use usual register	
Flipchart and pens	Check with venue	
Prepared flipcharts to put up	Check in each session what needs to be prepared in advance	
Handouts	Prepare photocopies of handouts for the Day (see session outlines)	
Prestik	For hanging flipchart notes	

2.1 Introduction to recovery & psychosocial rehabilitation

55 mins

ACTIVITY

- Recap
- Introduction to Recovery and Psychosocial Rehabilitation (PSR)

AIM

- Participants know the overall aim of the programme in promoting recovery

MATERIALS

- Handout 6

TIME MANAGEMENT

- Recap – 10 mins
- Activity 1 – 25 mins
- Activity 2 – 20 mins

INSTRUCTIONS

Recap

Recap what was covered in Day 1 by going round the group asking each person to share the most important thing they learned.

Activity 1: Recovery from schizophrenia

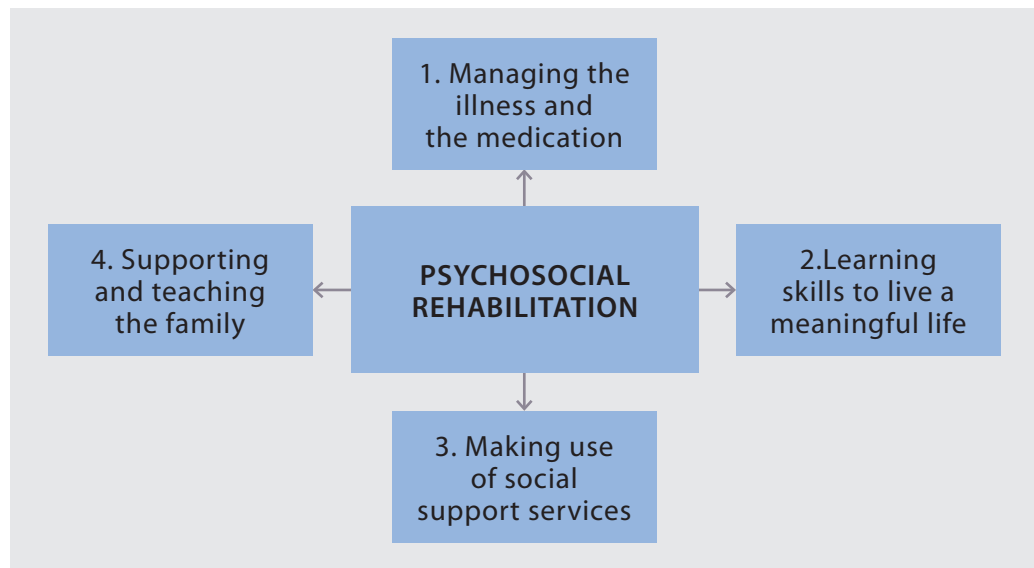
1. Explain that people with schizophrenia may have long periods when they are well, but then they may experience times when their symptoms reoccur. This is known as a relapse.
2. Explain that people with schizophrenia can also recover. But in this case recovery does not mean they are cured. Rather it means regaining a level of functioning that enables the person to find meaning and fulfillment in their life.
3. Highlight that 'Recovery' is the ultimate goal of this programme.
4. Divide participants into two groups. Assign each group to one of the stories in Handout 6.
5. Ask the groups to discuss the story answering the question 'what could 'recovery' mean to this person?'
6. After 15 mins bring the groups back together for a report back.
7. Note on a flipchart their ideas on what recovery means in these two situations.

Activity 2: Psychosocial Rehabilitation

1. Explain that to 'recover' people need support to manage their condition. This support is what we refer to as psychosocial rehabilitation.
2. Provide this definition of PSR using the flipchart you prepared:

Psychosocial rehabilitation is a process that enables people with mental illness to set and achieve goals for independent functioning in their own communities....

3. Explain that in this PSR programme, the support groups will fulfill this role. Draw up the diagram below on the flipchart, explaining each of the 'pillars' of PSR as you go along.
4. Ask participants for examples of what each pillar could mean, and how they could see themselves contributing.



5. Explain that in South Africa, where many people with schizophrenia are living in poverty, income generating activities are also an important part of PSR. Brainstorm with participants some of the income generating activities that support groups could be involved in. Highlight that income generating projects can take much time and commitment to get going, but they are an important goal of the PSR programme.
6. To end this session, emphasize that rehabilitation and recovery is an individual journey for each person. Being empowered to take up that journey is an important aspect of recovery. Ask participants to spend a few minutes quietly reflecting on how they will approach their role as facilitators. This questions will guide their reflection:
 - a. How can I work to empower the people I work with?
7. Ask each participant to privately write down their own personal commitments to empowering people in their support groups and encourage them to remember this as they progress through the training.
8. Summarize with the discussion points below.

DISCUSSION

- Recovery can mean very different things for different people
- Different people will have different levels to which they can recover. For example, not everyone will be able to recover to a point where they can be employed in a mainstream job
- It is important to be realistic about the level to which a person can improve.
- Often working or earning an income may be the most important part of recovery
- Each person will decide their own personal goals for recovery and facilitators are there to support them to reach those goals.
- Support group facilitators can act as a positive influence and help people to recover as far as possible
- They should avoid the temptation to use coercion, for example to force someone to be involved in a particular activity or to share personal experience.

Handout 6

Recovery Scenarios

Story 1

Sibonelo is a 45 year old man with schizophrenia. He was diagnosed 12 years ago, when he was arrested and hospitalised after damaging a shop. He has been in and out of hospital since then and for the last 5 years has been abandoned by his family. He has been homeless since then. He has had times over the years when he has taken medication and his symptoms have been better. But after they gave him pills his hands started to shake, his mouth became dry and he had a strange trembling in his legs. He is now convinced that the doctors and nurses are trying to poison him.

Discuss: What could recovery mean to Sibonelo?

Story 2

Patricia is a 30 year old mother of two young children. She worked as a secretary until she had an episode of psychosis and was hospitalised and diagnosed with schizophrenia 6 months ago. While hospitalised her mother in law took care of her children. Since being in hospital Patricia has been prescribed medications by her doctor and she has been taking them as directed. Her symptoms have greatly reduced and she is able to do most of the household tasks she used to. Her children have remained with her mother in law as she believes Patricia cannot deal with the stress of looking after two small children.

Discuss: What could recovery mean to Patricia?

2.2 Using the PSR facilitator guide

290 mins

NOTE: break for lunch according to programme

ACTIVITY

- Trainer presentation of Session Format
- Review and feedback on session content for each session

AIM

- Participants are familiar with the session format used in the Facilitator Guide

TIME MANAGEMENT

- Trainer presentation of Session format – 15 mins
- Review and presentation of session content by participants – 275mins

INSTRUCTIONS

Activity 1: Session Format (15 mins)

1. Ask the group to look at their Facilitator Guides. Explain that there is background information in the beginning. This can be a useful reminder of what they have covered in the training.
2. Next present the format of the sessions. Explain what is covered in each step. Ask: Why is each step important?
 - a. Step 1: Introduction and welcome
 - b. Step 2: Sharing of information by facilitator
 - c. Step 3: Sharing of experiences and group discussion
 - d. Step 4: Activity
 - e. Step 5: Closure
3. Make sure that participants understand the importance of members sharing experiences and not just hearing information from the Facilitator.

Activity 2: Getting Familiar With The Sessions

1. Explain that there are 17 sessions – 12 sessions for service users (patients) and 5 sessions for caregivers. There are fewer sessions for caregivers because they often have other commitments (e.g. work, childcare) that mean they don't have time to come to a group.
2. Allocate sessions to review to each participant (depending on how many participants you have, each one may have two or more sessions to review). Sessions 1 and 4 for caregivers are similar to the service users sessions so there is no need to repeat, only do Sessions 2, 3 and 5.
3. Their task is to review the session/s and give a brief presentation of what is covered to the rest of the group.
4. Allow 20 minutes for participants to review their sessions and then start the presentations (make a flipchart available for those who wish to use it). Run presentations in sequence according to the Facilitator Guide. Each participant has 10 minutes to present, 5 minutes for discussion/questions.
5. Thank each participant after their presentation. Use the summary points below for each session to add to the presentations.

6. Explain how Handouts are to be used in the sessions. These are available in SeTswana, and the Facilitator should explain slowly and clearly how each handout should be used to group members. They can then answer any questions and help the members to use the Handouts.
7. Ask whether there are any issues that need clarification. If you have participants (e.g. Health Promoters) who already run support groups for other chronic illnesses, ask them: How will these groups be different from those you already work on?
8. Round off the activity by highlighting the importance of facilitators preparing for each session in advance using the Facilitator Guide.

DISCUSSION

Summarise key points for each session after the participant's presentation.

Service User Session 1 Introduction to the PSR Programme and Goal Setting

- Session 1 sets the tone for the rest of the programme. We want members to feel comfortable, supported, motivated and interested
- It gives group members a chance to set goals they can work towards, to build their self esteem and help recovery

Service User Session 2 Understanding Our Schizophrenia Diagnosis

- This session aims to build members insight into their illness
- Through knowing correct information about the illness they can begin to take charge of managing the illness
- Understanding that hallucinations and delusions are part of the illness is important for insight

Service User Session 3 Understanding Medication

- Adhering correctly to medication is the first crucial step for helping members recover
- Knowing about side effects and that a doctor can help reduce these can help members to adhere to their medication. They will have to take medication for the rest of their lives
- While traditional medicine cannot reduce the symptoms of schizophrenia, traditional healers can be an important source of support and can help people understand their illness
- Group members should make sure that they consult a legitimate traditional healer rather than someone who may take advantage of them to make money.

Service User Session 4 Income Generating Activities

- The value of income generating activities is not only in the money they provide for members. It is also valuable for them to be doing something productive with their time
- It may not be possible for groups to get an income generating activity up and running in the duration of the programme, but Facilitators can support them towards doing this over a period of time.

Service User Session 5 Coping with Schizophrenia

- In this session group members can share their experience to help others recognize their warning signs and triggers
- Members also need to understand which warning signs indicate that they can cope on their own, and which ones mean they need to get help from a doctor or nurse

Service User Session 6 Substance Abuse

- People take drugs or alcohol for many reasons, often because they want to forget the difficulties in their life (e.g. poverty, unemployment)
- People with schizophrenia may feel that drugs or alcohol help to relieve their symptoms (e.g. help them to forget about the voices)
- It is not advisable to drink alcohol or take drugs whilst taking medication for schizophrenia
- Some people with schizophrenia stop drinking and taking drugs because they realize it has a negative effect on them
- Drug addiction is a disease of the brain, not a lack of will power
- People with addictions need support and people with schizophrenia who are also dependent on drugs need particular support. Blaming the person is not productive, the main thing is to help them to find a way out of their addiction.

Service User Session 7 Knowing Ourselves

- Knowing and understanding themselves better can help people to make better decisions and reach their goals.
- It helps people know their strengths, weaknesses, likes and dislikes
- Knowing your strengths and building your self esteem gives you hope and optimism to help face life's challenges
- People can get to know themselves better by observing and being aware of their moods, reactions and responses to what is happening around them.

Service User Session 8 Managing Anger, Stress and Conflict

When people don't know how to handle conflicts, communication breaks down and they blame each other. The most important things to remember about handling conflicts are:

- Choose the right time and place
- Say how you feel
- Listen to the other persons' side of the story
- Try to find a solution that suits both you and the other person

Service User Session 9 Dealing With Stigma and Discrimination

- Unfortunately, people with mental illnesses and their families suffer ill treatment from people in their community or even family members
- Group members cannot change the way other people act, but they can change the way they react to ill treatment and can try to keep up a positive self image
- Ill treatment of people with mental illness is often due to lack of understanding of what the illness is all about

Service User Session 10 Contributing to the Household

- Contributing to the running of our households is a way that we can all show love and care for our family members
- Some of the chores support group members can help with include:
 - Cooking
 - Cleaning
 - Gardening – e.g. looking after vegetables if they are grown
 - Running errands
 - Helping look after children

Service User Session 11 Money Management

- Managing their own money is an important way that group members can build their independence and self esteem
- This may not be possible for every group member and often a trusted family member is a good person to manage their money

Service User Session 12 Closure Session

- The closure session is a chance to thank members for their participation throughout the programme. It is also a chance to encourage them and motivate them to keep working towards their goals
 - It can be a good time for members to reflect on their journey and how they, and their lives, have changed during the programme.
 - They can continue to meet as a group, even if the facilitator is not there, and this is to be encouraged. They can also support each other in other ways by staying in contact.
-

Caregivers Sessions

Family/caregivers of people with schizophrenia play an important role in helping to care for their family members. But providing this care can also be stressful and place a burden on the caregiver. For this reason, they too need a space such as a support group where they can come and share experiences and coping strategies.

Caregiver Sessions 1 Understanding Our Relative's Illness and 4 Dealing with Stigma and Discrimination are similar to service users sessions 2 and 9, and do not need to be repeated.

Caregiver Session 2 Coping With Caring for A Person With Schizophrenia

- With the challenges they face, caregivers find different ways of coping
- This session is a chance for caregivers to realise they are not alone and that others face the same challenges
- Sharing experiences and ways of coping can help motivate caregivers to keep going

Caregiver Session 3 Family Conflict

- Knowing ways to help reduce conflict in the family can reduce the stress and burden caregivers face
- They can share and learn skills for being more supportive of their family member with schizophrenia, and knowing when they need to get help

Caregiver Session 5 Caring for the Caregiver

- Women usually have the majority of the caregiving role. This can place a great additional burden on them especially in families that already face hardships such as poverty.
- Increasing the role of men in caregiving means changing the way society views the caregiving role, but men too can find fulfilment from caregiving and this can reduce the burden on women in families
- One of the most important ways for caregivers to get a break is to ask for and accept help from people they trust
- Mental health is especially important to help caregivers cope with the day to day tasks of caregiving. Without good mental health the demands of caregiving can lead to stress, anxiety, depression and burnout
- Each person will develop their own ways of coping with their caregiving role
- One of the most important things in caregiver support groups will be for caregivers to have a chance to share their coping strategies with others
- Some ways that caregivers can take care of themselves include:
 - Doing something that gives them enjoyment and peace, even if it's only a 10-minute break.
 - Knowing when it is time to ask for help and asking before they find themselves in a crisis.

2.3 Accessing resources in the community

30 mins

ACTIVITY

- Discussion around need for accessing other resources
- Participant creation of local resource list

AIM

- Participants are able to link support group members to resources in the community

TIME MANAGEMENT

- Activity 1 – 30 mins

INSTRUCTIONS

Activity 1: Resources in the community

1. Explain that psychosocial rehabilitation links people to resources available in their community.
2. The first step is identifying the key resources which enable the person to manage their illness.
3. Explain that resources in the community may include family members, clinic staff, hospital staff, staff from the Department of Social Development and others.
4. In pairs, task the participants with coming up with a list of resources they could link group members with in their community.
5. After 20 minutes ask participants to share their ideas. Use this to create a list on the flipchart. Encourage participants to use this to create their own list in the space provided in their Facilitator Guide. Also introduce participants to the list of contacts already provided.

DISCUSSION

- Possible resources in the community include Businesses/Churches/Schools/Voluntary/Other Organizations
- For each resource, group members will need to know where it is, if they person can get to it on public transport and the name of the contact person.
- People with schizophrenia are very sensitive to stress. Standing in a queue for a long time, or not being able to understand directions is very stressful. It is important for them to know exactly what is to be expected.
- Facilitators can build up their Community Resource List through their own knowledge, by talking to people in the community, and by speaking to family members and the clinic sister.

2.4 Knowing when & where to refer

30 mins

ACTIVITY

- Group discussion on scenarios
- Orientation to referral forms

AIM

- Help participants to reflect on situations beyond their scope of influence
- Ensure participants know referral pathways to access in these cases

TIME MANAGEMENT

- Activity 1 – 30 mins

INSTRUCTIONS

Activity 1: Knowing when and where to refer

1. Introduce the activity by saying that a vital skill for PSR facilitators will be to know when a problem is beyond their ability to deal with and to refer appropriately.
2. There are some situations that participants will not be able to manage. In these cases they will need to refer the person to the appropriate service provider who is trained to deal with the issue.
3. Ask a participant to read out the following scenarios and ask for the group's ideas on what they could do if they were in the situation. (The advised action is given in brackets).

A member of your support group confides in you that he is being abused by his family. **(Refer to social worker)**

A member of your support group complains that she is unable to sleep at night and is suffering from chest pains. **(Refer to nurse at clinic)**

A member of your support group has seemed quiet and depressed for some weeks. When you ask what is wrong he says he feels like his life is not worth living anymore and is thinking seriously about ending his life. **(Refer to nurse/doctor at clinic. SUICIDE IS AN EMERGENCY. Take the patient to the nurse immediately)**

A female member of your support group who is a single mother of two children is struggling to feed them since she has been unable to get a child support grant. **(Refer to social worker)**

A member of your support group says since taking a new medication that they were prescribed, they have not been feeling good and have had shaking in different parts of their body. **(Refer to doctor or nurse at clinic)**

While walking one evening you see a male member of your support group breaking windows and throwing stones at people. **(Call police if the person is a danger to themselves or others)**

4. After these scenarios, hand out copies of the referral forms (Medication check referral form, Suicide Prevention referral form) and explain how these are used.

DISCUSSION

End this activity by emphasizing these points:

- Forming personal contacts with nurses at clinics, or social workers in the local community, will be helpful in ensuring easy referrals.
- It may be difficult to access a psychologist, but facilitators can still refer those in need to their local clinic who may then be able to refer them on to a psychologist.

2.5 Closure

15 mins

ACTIVITY

- Summary and time for questions/clarifications

AIM

- Participants have time to raise any issues or concerns

TIME MANAGEMENT

- Questions and clarifications – 15 mins

INSTRUCTIONS

1. Thank participants for their energy and participation today.
2. Ask if anyone has any questions or clarifications.
3. Go round the group asking each participant to share what is the most important thing they will be taking away with them today.
4. Go round the group asking them what they think will be the most challenging part of facilitating the sessions they have covered today. Which sessions do they think will be tricky? How will they deal with this?
5. Ask for 4 volunteers to prepare role plays for the first activity tomorrow. Give the volunteers information on the role play and allow them to look at the manual to prepare.
6. Remind participants of the start time for Day 3 training.
7. End the Days training in the way the group discussed.

Trainers reflection tool: Day 2

Some questions for today's reflection ...

What worked?

What did not go so well?

What aspect of training do we think we need to support tomorrow?

Who are you worried about in the group? What can you do to support this participant?

What do you appreciate about your co-facilitator?

What assistance do you need from him or her tomorrow?

» PSR facilitators training workshop: Day 3

3.1 Working with people with schizophrenia

75 mins

ACTIVITY

- Analysis of case study and role play
- Group discussion on traditional and religious beliefs

AIM

- Participants know how to respond to and help someone who is experiencing a relapse
- Participants know how to work with people with strong religious and traditional beliefs

MATERIALS

- Handout 7

TIME MANAGEMENT

- Recap – 10 mins
- Activity 1 – 20 mins
- Activity 2 – 15 mins
- Activity 3 – 25 mins

INSTRUCTIONS

Recap

Recap what was covered in Day 2 by going round the group asking each person to share the most important thing they learned.

Activity 1: Special Skills for Working With People With Schizophrenia

1. Introduce the activity by giving participants this background information:
 - a. In group meetings they may encounter members who are experiencing a relapse
 - b. Hearing voices that are not really there is often a symptom
 - c. The person may be quite frightened because the voices are very real to him/her.
 - d. Emphasize that there is a very small chance of this happening as they will be working with stable patients who are on medication.
 - e. However, it is important that they know how to deal with it should someone become violent. This applies not only to patients with mental illness but to anyone they work with.
2. Ask participants to get into group/pairs and discuss what they would do should someone in their group seem to be having a relapse and showing unusual/aggressive behaviour.
3. Ask for feedback from the pairs and refer participants to Handout 7
4. Go through the points on this page, discussing any items that did not come up in the group discussion. Highlight the importance of facilitators assessing whether there is a risk of violence and responding accordingly.
5. Also highlight to participants that it can be helpful for them to recognize when someone is hearing voices (e.g. if they mutter or talk to themselves) so that they can refer them for help before they get to the stage Lionel is at in the case study.

REMEMBER: It is very unlikely that facilitators will be faced with this scenario and they should not be fearful.

Activity 2: Role plays

1. The aim of this exercise is to show that the type of response can make a difference for the person with schizophrenia. Some can make the situation better and some will make it worse.
2. Ask the participants who volunteered to role play to come forward. Allow for discussion after each role play. Each one should take about 5 minutes.
 - a. Ask the participants to watch the actions of the person responding to Lionel
 - b. Ask participants to watch how Lionel responds.
 - c. After the role play ask the group to discuss how the person responding to Lionel behaved and what happened to Lionel.
3. After the second role play, ask participants which seemed to be the most helpful way of responding to Lionel and why?

» **Role Play 1 – Unhelpful response**

PSR FACILITATOR Good morning Lionel how are you feeling?

Lionel appears distracted and doesn't answer

PSR FACILITATOR (louder) Lionel, I said how are you feeling today?

LIONEL I feel frightened, he's trying to harm me again.

PSR FACILITATOR Who is trying to harm you Lionel? I don't see anyone.

Lionel looks fearful and says,

LIONEL You know who it is, everyone knows who it is, he's just told me so.

PSR FACILITATOR (appearing irritated) Lionel I don't have a clue what you are talking about, who told you they are going to harm you, I can't hear anyone. Stop talking like this people will think you are mad.

Lionel begins to look distressed

LIONEL Of course you know what I am talking about you can hear him, everyone can hear him, they must be able to he is shouting so loud.

PSR FACILITATOR (shouting) I have had it with you Lionel and your stupidity, you pretend to hear voices and you say they are trying to harm you when anyone can see that nobody is trying to harm you. Just stop being silly and pull yourself together.

Lionel becomes distressed and begins to cry and gets up and leaves.

PSR FACILITATOR Good morning Lionel how are you feeling?

Lionel appears distracted and doesn't answer

PSR FACILITATOR (speaking softly) Lionel you appear to be a little distracted are you feeling ok?

LIONEL I feel frightened, he's trying to harm me again.

PSR FACILITATOR (again speaking softly) Who is trying to harm you Lionel?

Lionel looks fearful and says,

LIONEL You know who it is, everyone knows who it is, he's just told me so.

PSR FACILITATOR Lionel are you hearing the voices of someone other than me talking to you at the moment?

Lionel looks puzzled

LIONEL yes I am and he is threatening to kill me! Can't you hear him?

PSR FACILITATOR No Lionel I can't hear the voice but I do believe that you can hear it and it sounds as though the things that the voice is saying to you are very frightening.

LIONEL Yes they are frightening! I try to tell myself that he can't hurt me but sometimes the voice is so loud I feel certain that he is going to get me.

PSR FACILITATOR That must be very distressing Lionel, you know it isn't uncommon for people to hear voices when there is nobody there talking to them.

LIONEL Isn't it? I thought I was the only one that heard voices like this.

PSR FACILITATOR No Lionel I have met lots of people that have heard voices like yours and many of them have been able to learn ways of making the voices less distressing.

LIONEL I wish I could stop this voice from bothering me, can you help me to do that?

PSR FACILITATOR I can't promise that I can make the voices stop completely but I can help you to cope with the voices to make it less distressing, would you like me to tell you more about how we might be able to do this?

Lionel appears less tense and more hopeful.

LIONEL Yes, I'd like you to tell me more about that.

DISCUSSION

Helpful things to do when someone is hearing voices, suspicious of others or expressing unusual beliefs:

- Listen to him/her.
- Talk calmly to him/her.
- Recognize that hearing voices and having strange beliefs are symptoms of schizophrenia, and can be very distressing for the person
- Encourage the person to do something that makes him/her feel more relaxed such as moving to a quieter place.
- Refer him/her to professional help (doctor, nurse, psychiatrist).

INSTRUCTIONS

Activity 3: Working With People Who Have Strong Religious and/or Traditional Beliefs

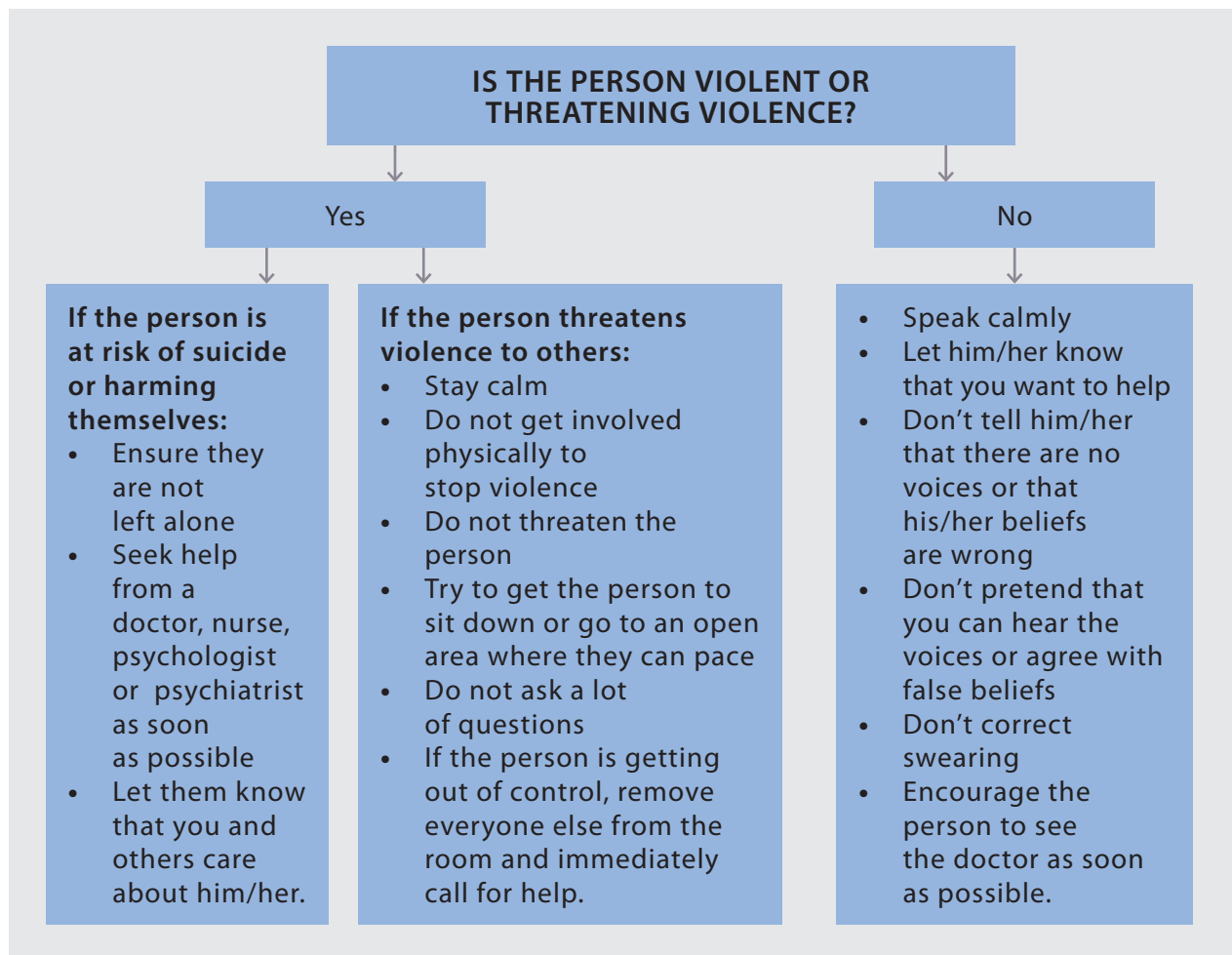
1. Spend 10 minutes discussing with the group what the common beliefs are around mental illness in their community. What do people believe causes mental illness? What do they believe can help/cure the illness? What is the role of traditional healers?
2. Next spend 10 minutes discussing with the group what religious beliefs may be held in the community around mental illness. Do people believe it is a result of possession by evil spirits? Do people believe that only God can heal them?
3. Thank the participants for sharing their ideas and experience. Summarise the discussion points below.
4. To end this activity ask participants to reflect quietly on the personal qualities of facilitators that would help them be accepting of other's beliefs. They should each write some of these down. Encourage them to make a commitment to bring these qualities to their work.

DISCUSSION

- In South Africa many people hold traditional beliefs about ancestors and the spirit world
- Because of the symptoms of schizophrenia often people believe it is caused by bewitching, curses or not performing rituals
- Traditional healers cannot effectively treat schizophrenia but they can be an important source of support
- Strong religious beliefs and ideas can sometimes be a symptom of the illness. For example a person may believe that God has spoken to them
- But faith in God and belonging to a religious group can also be an important way that people cope with their illness. We should not immediately think that a person's religious ideas are delusions.
- PSR Facilitators can emphasize the importance of taking medication even if people have different beliefs on what causes their illness

Handout 7

How to help a person who is hearing voices, suspicious of others, or expressing unusual beliefs



3.2 Schizophrenia in SeTswana

30 mins

ACTIVITY

- Group discussion

AIM

- Participants have begun to think about the language they will use when facilitating groups
- Participants will feel comfortable talking about schizophrenia and related issues in their home language

TIME MANAGEMENT

- Activity 1 – 30 mins

INSTRUCTIONS

Activity 1: Schizophrenia and SeTswana language

1. Introduce the activity by saying that in some languages there are not direct translations of many of the biomedical/Western medical terms people use when talking about schizophrenia.
2. Ask participants, from what they have learned, what are the most important words they will need to use in SeTswana for facilitating the support groups. What are the direct translations of these words? Why are they the most appropriate words to use?
3. If they don't come up, ask for ideas on what to use for these words:
 - a. Schizophrenia
 - b. Mental illness
 - c. Hallucination
 - d. Delusion
 - e. Relapse
 - f. Recovery
 - g. Early warning signs
 - h. Triggers
 - i. Coping
4. End the activity by encouraging participants to begin thinking about the language they will use in the sessions so they are comfortable and confident.

DISCUSSION

- For some English words relevant to schizophrenia and PSR there may not be a direct translation
- Its important to find the words that most strongly convey the same meaning and to be able to explain the English words to group members

3.3 Taking care of yourself

30 mins

ACTIVITY

- Group discussion
- Pairing up with 'buddy's'

AIM

- Participants have a 'buddy' facilitator who they can share experiences and challenges with, and gain support from

MATERIALS

- Prepared flipchart – Taking Care of Ourselves

TIME MANAGEMENT

- Activity 1 – 30 mins

INSTRUCTIONS

Activity 1: Taking Care of Ourselves

1. Ask participants why the role of a PSR facilitator might be challenging. Reasons include:
 - a. Working with people who face many challenges in their lives, especially poverty
 - b. Working with people who have had difficult life experiences, for example they may have experienced violence or neglect
2. Lead a discussion around emotional labour – what does emotional labour mean? How does it affect people?
3. Highlight that they are not expected to deal with these challenges alone. In addition to the supportive supervision structure of the programme, they can also use strategies to take care of themselves.
4. Ask the group for ideas of what they need to do as PSR Facilitators to take care of their own emotional wellbeing. Next put up the flipchart you prepared (see below)

Flipchart – Taking Care of Ourselves

 - a. Try not to take on people's problems
 - b. Accept what you can change, work on that
 - c. Speak to your supervisor to see if there is a way they can help
 - d. Take time to relax, do something you enjoy
 - e. Speak to a nurse or counsellor
 - f. Talk to friends and family
5. In the next part of the activity, participants should find a 'buddy'. This means everyone should pair up, it could be with someone they know, or with someone they don't know well yet. They will be 'buddy's' for the duration of the PSR programme. Use this opportunity to introduce the PeertoPeer feedback form and explain how it will be used and its benefits.
6. Beyond this, 'buddies' can act as a friendly ear to listen and support each other. They can also share cell phone numbers and keep in contact in this way. In their pairs, ask 'buddy's' to share around these issues:
 - a. How could we support each other as 'buddies'

3.4 Next steps for starting the programme

40 mins

ACTIVITY

- Group discussion and agreement on actions

AIM

- Participants are clear on the immediate actions they need to take to begin the programme

TIME MANAGEMENT

- Discussion of logistics – 15 mins
- Questions from group – 15 mins

INSTRUCTIONS

Activity 1: Logistics Discussion

1. Ask participants – what is the very first thing they need to do after completing the training?
2. What will be the next steps? Refer back to the diagram with the Facilitator roles and outputs.
3. It may help to prepare a flipchart with the following points in advance. You can then elaborate on these points in the discussion.

Support Groups Logistics

- Clinic contacts – working with nurses and community health workers
 - Date for initial meeting (all group members to be given appointment to collect medication on same day)
 - Tracing patients and/caregivers who do not come
 - Venue/s
 - Day, time, duration
 - Number of members
 - Number of groups
 - Supervisors and contact details
 - Tea/refreshments
4. After you have presented this information, ask the group if they have any questions or concerns.
 5. Address these as far as possible or if you are not able to answer them immediately, commit to clarifying the issue and getting back to the participants.

3.5 Closure of training

15 mins

ACTIVITY

- Sharing of feelings in relation to new role
- Feedback to participants
- Closure

AIM

- Participants feel confident and motivated for their new roles.

TIME MANAGEMENT

- 15 minutes for closure

INSTRUCTIONS

1. Go ground the group asking everyone to share one thing they are looking forward to in their new role and one thing they are apprehensive about. Try to normalise these concerns and help them address these.
2. Prepare cards with each participant's name on. Handout to each participant and ask them to keep it secret for now. Give them all 2 minutes to write something positive they have learned about this person, and why they will be a good PSR facilitator. Go round the group asking each participant to share what they wrote.
3. Thank participants for their energy and participation over the 5 days.
4. Share these take-home messages
 - a. Schizophrenia is a serious long term illness that has symptoms that make dealing with the daily challenges of living difficult for people with schizophrenia and their caregivers
 - b. There are effective treatments that can reduce the symptoms, but schizophrenia cannot be cured.
 - c. Patients and families need to learn to live with the challenges it presents, and still find meaning and fulfilment in their lives. This is what psychosocial rehabilitation is all about.
 - d. People with schizophrenia and their caregivers need to understand their diagnosis, their treatment programme, how to reduce their risk of relapse and how to deal with stigma and discrimination they may experience
 - e. Support groups provide a chance for patients and family members to share their experiences and coping strategies
 - f. They are also a chance for them to form friendships and offer and receive support
 - g. PSR Facilitators' role is to provide information and to guide the process of group members sharing experiences and supporting each other
5. Remind participants of the positive impact they can have on the lives of people with schizophrenia and their families, and motivate them to begin the programme.
6. End the training in the way the group discussed in the first session e.g. with a song or prayer.



PRIME Psychosocial Rehabilitation (PSR) Support Groups

Facilitator's Guide

**2014
PRIME
edition**



Name



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» Introduction

This document gives you a step by step guide on running group sessions for people with schizophrenia and their caregivers in your community.

- The first section has background information that you have covered in your facilitator training. This information can be useful to refer to as a reminder when you are preparing for the sessions
- There are 12 sessions for schizophrenia service users (patients), and 5 for caregivers
- Before each session, go through the step by step guide. You do not need to present the information word for word, use your own way of speaking and the language that comes naturally to you
- At the end of this guide are 5 Handouts. You can copy these to be used in the sessions. See the step by step guides for which Handout to use in which session
- Make sure you are clear on the steps, and the questions and discussions you will have. The document gives you an idea of time needed for each step. It's very important to give enough time for members to share their experiences
- Remember that each session needs to be facilitated in a caring and supportive way. People with schizophrenia can be sensitive to stress and conflict
- Remember to refer any member with specific needs to the right person – the nurse, doctor, psychologist, psychiatrist, social worker or another service provider in your community. If you have questions or concerns, contact your supervisor.

Working as a facilitator can be emotionally difficult. After each session, sit with another facilitator and debrief together using these questions.

After this session I feel because I

I am worried about

Anything we need to do differently next time

Anyone we need to refer to or discuss with the sister or doctor

Thank you for supporting me when

Next time

» Background information

What is mental illness?

- A mental illness is any illness that affects people's emotions, thoughts or behaviour
- Common mental illnesses are problems such as excessive fear and worry (anxiety) or unusually sad mood (depression)
- More severe mental illness can involve suspiciousness, violence, agitation and other unusual behaviours or experiences.

What is schizophrenia?

- Schizophrenia is a serious and lifelong mental illness. Both men and women can be affected
- Schizophrenia generally has its onset before the age of 30 years
- Someone with schizophrenia may behave in an unusual way, hear or see things that are not there, and have difficulty concentrating. This can cause difficulties in relationships with family and friends and keeping a job. People with schizophrenia may also abuse alcohol or drugs as a way of coping
- Someone with schizophrenia may have times when they are well and times when their illness becomes more severe (relapse)
- Treatment for schizophrenia is with antipsychotic medications (tablets or injections). These do not cure the illness but help to reduce the symptoms and to prevent relapses. These treatments may have side effects such as dry mouth, sleepiness, weight gain, dizziness, sadness/nervousness, shaking, amongst others
- People with schizophrenia may also commonly suffer from depression due to the way the illness impacts on their life.

What causes schizophrenia?

It is not known exactly what causes schizophrenia. It is most likely a combination of factors including:

- The illness running in families (genetic factors)
- Brain chemistry or an injury to the brain
- Environment and personal life experiences
- If a person is vulnerable to the illness there are factors that make it more likely that the illness will develop. Examples of these risk factors could be loss of a job, divorce, poverty, difficult relationships, problems at work, home or school, drug/alcohol abuse.

What are schizophrenia signs and symptoms?

- False beliefs e.g. thinking others are trying to harm them (delusions)
- Hearing voices that are not there (hallucinations)
- People with schizophrenia are said to have psychosis, which is a combination of hallucinations and delusions
- Strange behaviours e.g. talking to him/herself
- Social withdrawal e.g. avoiding contact with others, staying in their bedroom for long periods of time
- Inappropriate emotions e.g. laughing at something sad
- Loss of social skills
- Restlessness, walking up and down
- Aggression.

Despite what society says, people with schizophrenia are rarely dangerous. BUT if anyone you work with threatens to harm themselves or someone else, take them to a nurse or doctor immediately.

What do people with schizophrenia find difficult?

- Concentrating and thinking logically
- Interacting socially
- Forming and keeping relationships
- Working towards goals
- Taking care of themselves
- Dealing with stressful situations.

What is a relapse?

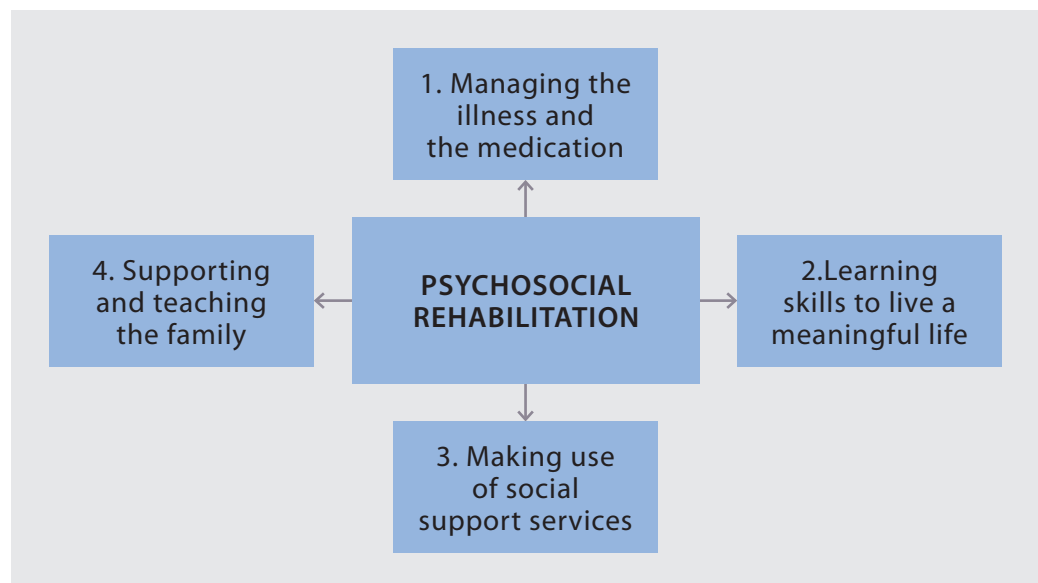
- If a person doesn't take their medication correctly or if they are stressed, the symptoms can get worse again - this is a relapse
- Even if someone takes their medication correctly they can still have a relapse, but this is less likely if they take their medication correctly.

What is recovery from schizophrenia?

- Schizophrenia is a lifelong illness so recovery does not mean cure. It means a person learning skills and gaining support to live a meaningful life in their community
- People with schizophrenia can work, be married, have families and be active in their community
- Often working and earning an income may be the most important part of recovery
- Even though every person's recovery journey is different, there are some factors that many people experience:
 - Hope - People need hope for the future to give them the strength to face challenges. Spirituality or religion is often a basis for hope
 - Social Functioning and Social Roles - People may take on or resume important social roles (e.g. partner/spouse, employee, caregiver)
 - Meaning and Purpose - Each individual will find their own meaning and purpose in life, often by being involved in productive activities (e.g. education, employment, hobbies, family life, parenting, relationships, community involvement, activism, spirituality).

What is Psychosocial Rehabilitation (PSR)?

- » Psychosocial rehabilitation enables people with mental illness to recover and to reach their optimal level of functioning in their own communities....



PSR Facilitators' and Supervisors' Roles

The diagram below outlines your role as a facilitator, and the role of your supervisor, as well as others involved in the programme like community health workers, nurses and facility managers. Use this diagram to help you in the process of setting up and running groups.

1 PSYCHOSOCIAL REHAB PROGRAMME INITIATION

Health Promoter arranges initial meeting with facility manager, nurses, community health workers, auxiliary social workers.

Outputs:

- Agree on date for start of programme (allowing time for initial meeting and tracing of users)
- Agree with facility manager on specified day for all schizophrenia patients to come to collect their medication and meet with Health Promoter.
- Health Promoter allocates date, time for each group session. Books clinic space as needed, creates programme with dates and times.

2 SERVICE USER REFERRAL

Nurse informs patients about group at scheduled appointments, schedules following month's appointment for all on same day, introduces the support group, refers to Health Promoter and reminds about following months medication collection. Health Promoter collects contact details, first language information, gives date for first meeting.

Output:

- Appointments for service users arranged for agreed day in following month
- Nurse keeps list of service users informed and communicates with Health Promoter

3 INITIAL MEETING WITH GROUP MEMBERS & IDENTIFICATION OF NON-ATTENDERS

Health Promoter and auxiliary social worker conduct initial meeting, introducing programme, aims and benefits, collecting service user names, addresses and contact number or contact for a caregiver. Checks list of attendees at initial meeting with clinic records of patients with diagnosis of schizophrenia, compiles list of those needing to be traced.

Outputs:

- List of service users who did attend initial meeting for CHWs to follow up with caregivers and invite to attend caregiver group
- List of service users who did not attend initial meeting for CHWs to trace (and contact caregivers at the same time)

4 SERVICE USER AND CAREGIVER TRACING & MOBILIZATION

Health Promoter informs CHWs of service users and caregivers to be traced and invited to attend group.

Output:

- CHWs inform service users and caregivers of the programme, give information on the programme and written invitation as well as programme with dates and times for sessions.

5 ALLOCATION TO SERVICE USER & CAREGIVER GROUPS

Output:

- Health Promoter develops attendance list based on those who have committed, and first languages of service users, allocates to groups if more than 10 participants, finalises programme/s accordingly.

6 GROUP COMMENCEMENT & IMPLEMENTATION

Health promoter/Auxiliary social worker conduct group sessions as per programme. CHW follows up non-attenders (home visits).

Outputs:

- Attendance registers for each session
- Confidentiality agreements signed at beginning of first session
- Copies of any referral forms retained

7 SUPERVISION

Supervisor attends first two sessions in programme, providing support and feedback. Supervisor and PSR Facilitator meet once a week for the first month and then twice a month for remainder of programme (face to face supervision meetings). PSR Facilitator 'buddies' provide feedback and support to each other following each session

Outputs:

- Peer to Peer supportive supervision form for each session

» Service user session outlines

Session 1: Introduction to the PSR programme & goal setting



STEP 1 Start of session

5 mins

- Introduce yourself and explain a bit about your background
- Ask members to introduce themselves and share one interesting fact about themselves
- Thank members for being present and explain that this programme is about walking with them in a journey to improve aspects of their lives.



STEP 2 Sharing information

15 mins

- Explain that all the group members have schizophrenia
- This is a programme to help them learn more about their illness and how to cope with it
- Emphasize confidentiality and ask members to sign the confidentiality agreement
- They will not be provided with a job through the support group but they may decide to join together to do something that earns an income
- Explain that there will be 12 sessions of approximately 45 minutes each week. Check that everyone has been given a programme of the sessions
- Everyone will be encouraged to share their experiences and learn from each other
- Ask if anyone has any questions and answer those that come up
- Explain that each group member needs to set goals for what they will achieve in the programme
- Give some examples of what goals could be.



STEP 3 Sharing experiences

20 mins

Ask the group:

- What made them decide to join the group?
- What do they hope to gain from the group?
- What goals could they set for themselves?
- Thank each member and encourage them to work towards these goals.

**STEP 4** Activity

5 mins

- Ask members to turn to the person next to them and talk about their goals or what they would like to get out of the programme
- Explain that it is important to go back to these goals over time to see how they are progressing
- Emphasize that this is not about judging their progress, but about seeing if there are additional ways that they can be supported
- Ask members to share their goals
- Anyone who does not want to share at this time does not have to
- Encourage those who are comfortable with writing to write down their goals on Handout 1.

**STEP 5** End of session

5 mins

- Ask the group how they would like to close their sessions every week
 - Would they like a prayer, or a song, or something else?
- Close the session appropriately
- Remind the members of the time for next week's session.

Session 2: Understanding our schizophrenia diagnosis



STEP 1 Start of session

5 mins

- Open the group in an appropriate way (e.g. song, prayer)
- Remind them this is a safe space for them to learn and share
- Encourage everyone to be involved and participate
- Are there any pressing issues people want to bring up?



STEP 2 Sharing experiences

20 mins

Ask the group:

- How did they come to know that they had schizophrenia?
- What were their experiences in hospital?
- What do they understand to be the causes of their illness?
- What symptoms do they experience?
- How do they could cope with these symptoms? (Add to their discussion of how they could cope by sharing the coping strategies given in Handout 2)
- Do they have any other chronic (long term) illnesses – like diabetes or high blood pressure? How do they cope with these?



STEP 3 Sharing information

10 mins

- Thank members for what they have shared
- Explain that you are going to share some information on schizophrenia
- Hand out the schizophrenia patient information leaflet. Encourage members to give these leaflets to their family members
- Share the information points below:
 - Schizophrenia is a lifelong mental illness
 - It could happen to anyone, some people are more vulnerable
 - It is not known exactly what causes it, genetics and stress are factors
 - It is a disease of the brain. Conflict in the family and drug abuse make the illness worse.

- Symptoms can include:
 - Hallucinations (hearing or seeing things that aren't there)
 - Delusions (false beliefs)
 - Strange behaviours
 - Inappropriate emotions
 - Loss of social skills
 - Social withdrawal
 - Restlessness
 - Aggression
- Antipsychotic medications can help to reduce these symptoms
- A relapse is when symptoms reoccur or get worse
- Recovery from schizophrenia doesn't mean the illness is cured. It means a person learning skills and gaining support to live a meaningful life in their community.



STEP 4 Activity

10 mins

- Give each member a piece of paper and ask them to draw something that shows how they cope with their symptoms. When everyone is done, ask for volunteers to share their drawings and what they mean. Add to their discussions with the information on Handout 2
- Now that members have had a chance to get to know each other better they can share cell phone numbers if they are comfortable doing this. This way they can support each other outside of group sessions.



STEP 5 End of session

5 mins

- Thank members for sharing their experiences and supporting each other
- Encourage members by highlighting positive progress they are making
- Close the session in the agreed way
- Remind the members of the time for next week's session.

Session 3: Understanding medication



STEP 1 Start of session

10 mins

- Open the group in an appropriate way (e.g. song, prayer)
- Remind them this is a safe space for them to learn and share
- Encourage everyone to be involved and participate
- Are there any pressing issues people want to bring up?
- Explain that today they will have a doctor/nurse who will give them information on their medication and answer questions. They should feel comfortable talking to this person as they are experienced in working with people with schizophrenia and they want to help them understand their medication better. Introduce the doctor/nurse to the group. Allow them as much time as needed to give information and answer questions
- If you do not have a doctor or nurse present, use the session guideline below.



STEP 2 Sharing experiences

20 mins

Ask the group:

- What medication do they take? Tablet or injection?
- How has medication helped?
- Have they used traditional medicine?
- What does it feel like to know you have to take medication for the rest of your life?
- What side effects do they have?
- How do they cope with side effects?

Ensure that each member gets a chance to speak if they want to.



STEP 3 Sharing information

10 mins

- Thank members for what they have shared
- Explain that you are going to share some information on schizophrenia medication
- Medications for schizophrenia are called antipsychotics. They can be tablets or injections. The doctor decides on which to prescribe
- Some of the side effects that are known to go with antipsychotics are dry mouth, shaking, sleepiness, weight gain, dizziness, sadness/nervousness, decreased sexual ability, muscle spasms, changes in menstrual periods. Different people can have different side effects

- For serious side effects they should always see the doctor, and should never stop taking medication suddenly
- The doctor may change the medication to a different one to avoid side effects. Or he/she may prescribe another medication to deal with the side effects. It can take time for the doctor to get the medication right
- Medication should not be taken with alcohol or other drugs
- Some other medications (prescribed, traditional or over the counter) can affect the antipsychotic medication so they should always let the doctor know what medication they are on
- If they find it difficult to remember to take their medication, they can ask a family member to help them
- People who take antipsychotics can be at risk for diabetes and heart disease if they put on weight so they should consult their doctor if they notice weight gain or an increase in stomach fat
- Traditional medicine cannot reduce the symptoms of schizophrenia, but traditional healers can help those who choose to see them understand how to live with their illness.



STEP 4 Activity

5 mins

- Give members Handout 3 on 'My Medication'. Let them discuss with each other and fill this in. Many may not be sure of the name of the medication. They can take this handout and check with the nurse or doctor at their next appointment. Encourage those who are not comfortable with writing to work together with someone who is, or to work with a facilitator
- Encourage group members to keep this paper with them as a reminder to take their medication.



STEP 5 End of session

5 mins

- Thank members for sharing their experiences and supporting each other
- Encourage members by highlighting positive progress they are making
- Close the session in the agreed way
- Remind the members of the time for next week's session.

Session 4: Income generating activities



STEP 1 Start of session

5 mins

- Open the group in an appropriate way (e.g. song, prayer)
- Remind them this is a safe space for them to learn and share
- Encourage everyone to be involved and participate
- Are there any pressing issues people want to bring up?
- Explain that one of the aims of this programme is to help them come together to work on an income generating project
- If you have a partner/organisation who will help group members do this introduce them to the group now and give them a chance to explain their project. Then go to Step 3 in the session guide
- If you do not have a partner organisation start from Step 2 below.



STEP 2 Sharing experiences

20 mins

Ask the group to share:

- What income generating projects do they know in their community?
- Share some examples - food gardens, chicken rearing projects, second hand clothes sales, plastic/glass recycling projects, handcraft sales
- What is needed in their community?
- What skills or experience do they have?
- What work would they enjoy?

Ensure that each member gets a chance to speak if they want to.



STEP 3 Sharing information

10 mins

- Being productive can help people with schizophrenia in their recovery
- Even if they are not working with a partner organization, they may be able to apply to for government funding to start an income generating project. Explain that you as facilitator can support them in doing this
- The group needs to decide on a project that they are interested in and motivated to work on together.

**STEP 4** Activity

10 mins

- Explain that any project they work on is for their ownership, and you as the facilitator will not direct them in what to do. They should spend some time after the session talking about opportunities and ideas for a project, and if possible, agreeing on a project to work on. They will have a chance to check their progress at the beginning of each session from now
- Some group members may also like to talk about possible work opportunities and how they can go about finding these. Finding a job can be difficult. When they feel discouraged they can talk to other support group members who may be facing the same challenges.

**STEP 5** End of session

5 mins

- Explain that you will set aside time at the end of each session that follows for the group to discuss their project
- Close the session in the agreed way
- Remind the members of the time for next week's session.

Session 5: Coping with schizophrenia



STEP 1 Start of session

15 mins

- Open the group in an appropriate way (e.g. song, prayer)
- Remind them this is a safe space for them to learn and share
- Encourage everyone to be involved and participate
- Are there any pressing issues people want to bring up?
- Dedicate the first 15 minutes of the session to discussing the group's income generating project. Then introduce today's topic – learning to cope better with their illness.



STEP 2 Sharing experiences

15 mins

Ask the group to think about a time when they had a relapse:

- What made them realise they were not doing well?
- What made their family realise they were not well?
- What caused them stress?
- What were other triggers of the relapse? (Add to their discussion using the information in Handout 4. Ask if group members can identify with any of these)
- How do they cope when they feel they are going to relapse?

Ensure that each member gets a chance to speak if they want to.



STEP 3 Sharing information

10 mins

- Thank the group for what they have shared
- Explain that there are 3 ways to help them cope:
 - Knowing their early warning signs and triggers
 - Living a healthy lifestyle
 - Using coping skills
- Each person has a set of early warning signs that usually occur before a relapse. These are called the "signature signs". People who learn their signature signs and what triggers them are much less likely to relapse
- Living a healthy lifestyle means taking their medication as directed, avoiding stress and misuse of alcohol or drugs and eating well, exercising and doing things that make them happy (e.g. seeing friends/family)
- Coping skills can be built by thinking about what has worked in the past and learning from others, as they have begun to do in this session
- Group members should always get help from a doctor or nurse if they feel they are not able to cope with the symptoms or if they are getting worse.

**STEP 4** Activity

5 mins

- Ask members to turn to the person next to them and talk about their own 'signature signs' and how they cope with these. Ask the pairs to talk about ways they could help each other cope
- Ask group members to commit to trying some of the ways of coping that have been shared in the group today and seeing how they work for them.

**STEP 5** End of session

5 mins

- Thank members for sharing their experiences and supporting each other
- Encourage members by highlighting positive progress they are making
- Close the session in the agreed way
- Remind the members of the time for next week's session.

Session 6: Substance abuse



STEP 1 Start of session

5 mins

- Open the group in an appropriate way (e.g. song, prayer)
- Remind them this is a safe space for them to learn and share
- Encourage everyone to be involved and participate.
- Are there any pressing issues people want to bring up?
- Dedicate the first 15 minutes of the session to discussing the group's income generating project
- Introduce today's topic saying that you will be talking about substance abuse and addiction, an issue that many people face. You are not here to judge anyone but rather to give support.



STEP 2 Sharing experiences

15 mins

Ask the group:

- Have they used alcohol and/or drugs in the past?
- What led them to do this?
- How did the alcohol/drug use affect them? Did it affect their medication?
- Did it cause problems for them?

Remember: Addiction is a serious illness. Talking about experiences of addiction may be difficult. No one should share anything they are not comfortable with. Refer anyone who has a problem with drugs or alcohol to the appropriate support in your community.



STEP 3 Sharing information

10 mins

- Drug addiction is a disease of the brain, not a lack of will power
- People take drugs for many reasons, often because they want to forget the difficulties in their life (e.g. poverty, unemployment)
- People also take drugs to avoid boredom, to deal with stress, to escape from reality, to avoid family problems
- They may feel that drugs or alcohol help to relieve their symptoms (e.g. help them to forget about the voices)
- Any person who becomes addicted to a drug/alcohol needs professional help. It can be a life long struggle and should not be underestimated.
- Not every person who uses alcohol or drugs will become addicted, but they affect antipsychotic medications, so people with schizophrenia should avoid using these substances.

**STEP 4** Activity

5 mins

- This week, ask members to talk with another member of the group about how often they use alcohol or other substances and if they could stop completely. If they do not use substances themselves, do people around them? How does this affect them? Ask members if they can commit to get help if they are abusing drugs or alcohol.

**STEP 5** End of session

5 mins

- Thank members for sharing their experiences and supporting each other
- Encourage members by highlighting positive progress they are making
- Close the session in the agreed way
- Remind the members of the time for next week's session.

Session 7: Knowing ourselves



STEP 1 Start of session

15 mins

- Open the group in an appropriate way (e.g. song, prayer)
- Remind them this is a safe space for them to learn and share
- Encourage everyone to be involved and participate
- Are there any pressing issues people want to bring up?
- Dedicate the first 15 minutes of the session to discussing the group's income generating project. Then introduce today's topic.



STEP 2 Sharing experiences

15 mins

Introduce the discussion saying that over the last few weeks the group has talked a lot about the illness, symptoms and medication. But we as people we are not just our illnesses. We have many other parts to ourselves (e.g. our relationships and friendships, our interests). So today we would like to talk about some of these things.

Ask the group to share:

- What do they like to do?
- What makes them feel good about themselves?
- What are their personal strengths and skills?
- What are their hopes/dreams for the future?

Ensure that each member gets a chance to speak if they want to. No one should feel they have to share anything they are uncomfortable with.



STEP 3 Sharing information

10 mins

- Thank the group for what they have shared
- Emphasize that everyone, INCLUDING those with mental illnesses, has strengths
- Strengths could be practical skills, knowledge, and motivation that can be used in some way to help them meet their goals
- Self esteem is what we believe about ourselves. We can build our self esteem by appreciating and building on our strengths
- Knowing your strengths and building your self esteem gives you hope and optimism to help face life's challenges.

**STEP 4** Activity

5 mins

- Using Handout 5, ask members to share in pairs about their strengths and dreams.

**STEP 5** End of session

5 mins

- Thank members for sharing their experiences and supporting each other
- Encourage members by highlighting positive progress they are making
- Close the session in the agreed way
- Remind the members of the time for next week's session.

Session 8: Managing anger, stress & conflict



STEP 1 Start of session

15 mins

- Open the group in an appropriate way (e.g. song, prayer)
- Remind them this is a safe space for them to learn and share
- Encourage everyone to be involved and participate
- Are there any pressing issues people want to bring up?
- Dedicate the first 15 minutes of the session to discussing the group's income generating project. Then introduce today's topic
- Explain that anger and stress are part of everyone's lives, but they can be especially hard to deal with for people with a mental illness.



STEP 2 Sharing experiences

15 mins

To start this session, ask for a volunteer to share a recent experience of when they got angry with someone.

- What did they do?
- And what were the consequences of their actions?
- How would they like to do things differently?

Thank this volunteer for sharing and ask others in the group to make suggestions/ share experiences.

Then ask the group members to share:

- What causes conflict between them and their family members?
- How could they change the way they react to be more positive?
- What makes them feel stressed?
- What do they do to feel better when they are stressed?



STEP 3 Sharing information

10 mins

- Anger is something that happens in everyone's lives but it can be dealt with in a positive way. It helps to:
 - Know what provokes you
 - Take deep breaths before saying or doing anything
 - Give the other person time to respond
 - Learn how to listen
 - Express your emotions calmly
 - When the discussion is over, end your anger that day, don't carry it with you
- Conflicts arise in all families but in families where a member has a mental illness there can be more conflict
- When people don't know how to handle conflicts, communication breaks down and they blame each other
- The most important things to remember about handling conflicts are to listen to the other persons' side of the story and try to find a solution that suits both you and the other person
- People with schizophrenia and their family have a lot of stress in their lives
- Positive ways of coping with stress include:
 - Getting some exercise – doing something you enjoy
 - Finding a Hobby – reading, cooking, games
 - Spending time in prayer/meditation
 - Seeing the doctor /counsellor/ psychologist
 - Eating correctly (3 balanced meals a day)
 - Getting enough sleep (6 – 8 hours)
 - Setting goals for yourself
 - Talking to others and socialising.



STEP 4 Activity

5 mins

- Ask group members to talk in pairs about activities they could do in the next week that would make them feel less stressed (e.g. reading, listening to music, talking to a friend).



STEP 5 End of session

5 mins

- Close the session in the agreed way
- Remind the members of the time for next week's session.

Session 9: Dealing with stigma & discrimination



STEP 1 Start of session

15 mins

- Open the group in an appropriate way (e.g. song, prayer)
- Remind them this is a safe space for them to learn and share
- Encourage everyone to be involved and participate
- Are there any pressing issues people want to bring up?
- Dedicate the first 15 minutes of the session to discussing the group's income generating project. Then introduce today's topic
- Explain that those with mental illness often face poor treatment by family members and others in their community. We call this stigma and discrimination
- While they may not be able to change the way other people treat them, they can control how they deal with this poor treatment, so that it does not affect them negatively.



STEP 2 Sharing experiences

15 mins

Ask the group members to share:

- What experiences have they had where they have been treated badly by family or others?
- How does this make them feel?
- How have they dealt with this?
- How could they deal with this in a positive way in the future?



STEP 3 Sharing information

10 mins

- A positive way to deal with negative experiences is to use problem management:
 - Understand the problem
 - Find different ways to deal with the problem
 - Decide on the best way, and then use it
- Dealing positively with bad treatment also means having 'healthy thinking' about themselves. This means accepting that they cannot change the way people see them, but they that they should still see themselves as a valuable person. The illness does not define them and they can recover and have a meaningful life
- It can help to know that stigma and discrimination are often due to lack of knowledge and prejudice, these problems lie with the other person not within themselves.

**STEP 4** Activity

5 mins

- In pairs, ask members to share if they have been treated poorly recently? How could they cope with this in a positive way?

**STEP 5** End of session

5 mins

- Close the session in the agreed way
- Remind the members of the time for next week's session.

Session 10: Contributing to the household



STEP 1 Start of session

15 mins

- Open the group in an appropriate way (e.g. song, prayer)
- Remind them this is a safe space for them to learn and share
- Encourage everyone to be involved and participate
- Are there any pressing issues people want to bring up?
- Dedicate the first 15 minutes of the session to discussing the group's income generating project. Then introduce today's topic
- Emphasize that even if they are not working in a regular job, the work they can do in their own homes is very valuable
- Having an extra pair of hands can make things easier for the whole family.



STEP 2 Sharing experiences

15 mins

Ask the group members to share:

- What are they good at around the house?
- What jobs do women usually do around the house? Could men do these too? How would that help?
- How would your family members feel if you did more work in the house?

Ensure that each member gets a chance to speak if they want to.



STEP 3 Sharing information

10 mins

- Often our family members, especially the women (the mothers and sisters) work extremely hard to keep the household going. This work is sometimes not recognized because it is not paid work
- Contributing to our households is a way that we can care for our family members
- Some of the chores support group members can help with include:
 - Cooking
 - Cleaning
 - Gardening – e.g. looking after vegetables
 - Running errands
 - Helping look after children
- Although some of these are seen as 'women's work' men can also do these chores and contribute to their families in this way.

**STEP 4** Activity

5 mins

- Ask members to talk in pairs about one extra chore in the household they could help with this week. They will have a chance to give feedback in the next session.

**STEP 5** End of session

5 mins

- Close the session in the agreed way
- Remind the members of the time for next week's session.

Session 11: Money management



STEP 1 Start of session

15 mins

- Open the group in an appropriate way (e.g. song, prayer)
- Remind them this is a safe space for them to learn and share
- Dedicate the first 15 minutes of the session to discussing the group's income generating project and how things went with their task to contribute to their homes. Then introduce today's topic
- Are there any pressing issues people want to bring up?
- Introduce today's activities saying that they will help members to save money and budget.



STEP 2 Sharing experiences

15 mins

Ask the group members to share:

- Who manages the money from their grant?
- How do they try to save money?
- Where do they shop to save money?
- How could they help each other to save?
 - For example they could start a saving 'club' where they set up an account that everyone contributes to and at the end of the year they use the money for something they agree on.



STEP 3 Sharing information

10 mins

- Explain that setting a monthly budget can help to make sure their grant lasts the month
- A simple way to do this is to have a number of envelopes, with one envelope containing money for one thing. For example you would have an envelope for rent, one for electricity, one for food, one for clothing, one for transport etc. This way it is easier to keep control over what you are spending. It's important to try not to 'dip in' to other envelopes. You can also have an envelope for 'saving' that you don't touch
- Ask members what envelopes they would need if they wanted to budget in this way
- Budgeting and saving can help them avoid going into debt, for example with store cards or through taking loans from loan sharks.

**STEP 4** Activity

5 mins

- Ask members to turn to the person next to them and share any tips they have for making their money go further.

**STEP 5** End of session

5 mins

- Close the session in the agreed way
- Remind the members of the time for next week's session.

Session 12: Closure session



STEP 1 Start of session

15 mins

- Open the group in an appropriate way (e.g. song, prayer)
- Remind them this is a safe space for them to learn and share
- Encourage everyone to be involved and participate.
- Are there any pressing issues people want to bring up?
- Dedicate the first 15 minutes of the session to discussing the group's income generating project
- Explain that today is the last session in the programme but that they can still continue meeting as a group to support each other.



STEP 2 Sharing experiences

15 mins

Ask the group members to share:

- What have they learned in the programme?
- Have there been changes in their lives?
- What are their plans for the future?



STEP 5 End of session

10 mins

- Thank all members for their participation throughout the programme.
- Encourage them to keep meeting and to support each other by staying in contact
- Encourage them to keep working on their income generating project
- Close the final session in the agreed way.

Top Tips For Facilitating PSR Support Groups

- Be prepared. Review the topics and questions in the Session guidelines
- As people begin arriving, be sure to make eye contact and say hello, greeting them by name
- Start the meeting on time if possible to encourage other members to be prompt
- Encourage members to listen to each other
- Encourage members to offer support to one another. For example, you could say "Catherine, what can you say to Bonang that might help?"
- Encourage members to talk about themselves
- Encourage an atmosphere where members feel comfortable talking about themselves and their experiences – this gives others the chance to give support, ideas and help
- Emphasize the importance of confidentiality. So members feel safe to talk about their experiences and problems
- Help members solve problems. This is not the facilitator's responsibility, but through discussion and sharing of experiences, members may be able to help each other solve problems they face
- Try to help members focus on the positive aspects of their lives
- Don't let one member dominate and use the meeting as a chance to air all their complaints and problems. Some people naturally like talking, others have to be brought out of their 'shells'
- Encourage outside contact among members. Members can offer support to each other outside of meetings. Members can share cell phone numbers and can contact and support each other outside of the meetings.

» Caregiver session outlines

Session 1: Understanding our relative's illness



STEP 1 Start of session

5 mins

- Introduce yourself and explain a bit about your background
- Ask group members to introduce themselves and share one interesting fact about themselves
- Thank members for being present and explain that this programme is about helping them to cope with caring for their relative with schizophrenia
- They will meet once a month for approximately 45 minutes.



STEP 2 Sharing experiences

20 mins

Ask the group:

- How did they find out that their relative had schizophrenia?
- Who told them the diagnosis?
- What information were they given?
- What do they understand to be the causes of the illness?
- What do they know about the medication for the illness.



STEP 3 Sharing information

10 mins

- Thank members for what they have shared
- Hand out the schizophrenia information leaflet if you have these
Encourage members to give these leaflets to other family members so they can know more about the illness
- Share the information points below:
 - Schizophrenia is a lifelong mental illness
 - It could happen to anyone, some people are more vulnerable
 - It is not known exactly what causes it, genetics and stress are factors. Conflict in the family and drug abuse make the illness worse. It is not caused by bewitching or curses, it is a disease of the brain

- Symptoms include:
 - Hallucinations (hearing or seeing things that aren't there)
 - Delusions (false beliefs)
 - Strange behaviours
 - Inappropriate emotions
 - Loss of social skills
 - Social withdrawal
 - Restlessness
 - Aggression
- Antipsychotic medications can help to reduce these symptoms. They can be tablets or injections. There are different medications for schizophrenia. The doctor decides on which to prescribe
- These medications can have side effects like shaking, dry mouth and weight gain. If the person is concerned about side effects they should see the doctor or nurse instead of just stopping the medication
- Caregivers have an important role in reminding or assisting their family members in taking their medication
- A relapse is when symptoms reoccur or get worse e.g. if the person does not take their medication as directed.



STEP 4 Activity

10 mins

- Sometimes people with schizophrenia are misunderstood by their family members because they don't know about the illness. Ask members to turn to the person next to them and share the most important things they have learned today.



STEP 5 End of session

10 mins

- Thank members for sharing their experiences and supporting each other.
- Close the session in an agreed way
- Remind the members of the date and time for the next session.

Session 2: Coping with caring for a person with schizophrenia



STEP 1 Start of session

5 mins

- Welcome group members to this session
- Ask if anyone has any pressing issues
- Acknowledge that caring for someone with schizophrenia can be difficult. Explain that today's session is a chance for them to learn from each other about ways to cope.



STEP 2 Sharing experiences

20 mins

Ask the group:

- How do they know when their relative is not well?
- What do they do when they see these signs/symptoms?
- How do they feel when their relative becomes unwell?
- How do they cope with looking after their relative as well as all the other tasks in their household?

Ensure that each member gets a chance to speak if they want to.



STEP 3 Sharing information

10 mins

- Thank the group for what they have shared
- Explain that each person with schizophrenia has a set of early warning signs that usually occur before the symptoms return in full. Share some of the common early warning signs/triggers
- Explain that as caregivers, knowing the early warning signs can help them make sure the person they care for gets the support they need to avoid a relapse
- This involves helping their relative to take their medication, avoid stress and misuse of alcohol or drugs as well as eating well, exercising and doing things that make them happy (e.g. seeing friends/family)
- If the symptoms seem to get worse, they should always get help from a doctor or nurse
- Thank the group for the experiences they have shared. We can all learn ways of coping with challenges in our lives from hearing how other people deal with them. Encourage them to learn from what others have shared and to apply this to their own lives.

**STEP 4** Activity

10 mins

- Caregivers can be an important source of support for each other. In pairs, ask members to share practical ways they could support each other (e.g. they could help take care of another member's children on a certain day)
- Encourage them to share phone numbers and to contact each other outside of the sessions to offer and receive support as needed.

**STEP 5** End of session

5 mins

- Thank members for sharing their experiences and supporting each other
- Remind the members of the date and time for the next session.

Session 3: Family conflict



STEP 1 Start of session

5 mins

- Welcome group members to this session
- Ask if anyone has any pressing issues they would like to discuss
- Explain that conflict/arguments can lead to stress for caregivers and it increases the chances that their relative will have a relapse
- Learning to communicate better can help reduce conflicts.



STEP 2 Sharing experiences

20 mins

Ask the group members to share:

- What causes conflict between them and their family member with schizophrenia?
- How have they dealt with this in the past?
- What could they do to deal with the conflict in a more positive way?

Ensure that each member gets a chance to speak if they want to.



STEP 3 Sharing information

10 mins

- Conflicts arise in all families but in families where a member has a mental illness there can be more conflict
- When people don't know how to handle conflicts, communication breaks down and they blame each other
- In a conflict situation, we have a choice how to react. We can either give in, fight, or negotiate a good solution
- The most important things to remember about handling conflicts are to listen to the other persons' side of the story and try to find a solution that suits both you and the other person
- You can say how you feel, and also try to show you understand how the other person feels, then you can suggest a compromise.

**STEP 4** Activity

10 mins

- In pairs, ask group members to share the most important thing they heard today. How could they try to apply this to their own lives?

**STEP 5** End of session

5 mins

- Thank members for sharing their experiences and supporting each other
- Remind the members of the date and time for the next session.

Session 4: Dealing with stigma & discrimination



STEP 1 Start of session

5 mins

- Welcome group members to this session
- Ask if anyone has any pressing issues they would like to discuss
- Acknowledge that caregivers are often mistreated because of their association with a person with a mental illness. We call this stigma and discrimination.



STEP 2 Sharing experiences

20 mins

Ask the group members:

- Has your mentally ill relative been treated badly? How did this make you feel?
- Are people in your community aware that you care for a mentally ill person?
- Have you been mistreated because of this?
- How did that make you feel and how did you cope?

Ensure that each member gets a chance to speak if they want to.



STEP 3 Sharing information

10 mins

- Some common ways that caregivers of people with schizophrenia are mistreated are by not being included in family functions, being ignored or verbally abused, or being blamed by doctors or nurses when a relapse happens
- Caregivers can start to have negative feelings towards those they care for
- Caregivers need to deal with these negative feelings because people with schizophrenia need patience and love from those who care for them
- It can help to know that their difficult behaviour (e.g. when they do not do what is expected of them) is not done intentionally but is part of their illness
- Helping them to take their medication as directed can help them to function better.

**STEP 4** Activity

10 mins

- Highlight that people's attitude towards you cannot always be changed but your response to these attitudes can be changed. Ask pairs to talk about how they can cope when they or their family member are treated badly.

**STEP 5** End of session

5 mins

- Thank members for sharing their experiences and supporting each other
- Remind the members of the date and time for the next session.

Session 5: Caring for the caregiver



STEP 1 Start of session

5 mins

- Welcome group members to this session
- Ask if anyone has any pressing issues they would like to discuss
- Acknowledge that caregiving is a form of work, and that caregivers also need to be able to take care of themselves. This is for their own wellbeing and for the person they care for, who relies on them.



STEP 2 Sharing experiences

20 mins

Ask the group members:

- What do you find most difficult in caring for your relative?
 - Do you have people you can call on to help?
 - What causes you stress?
 - What makes you feel sad/hopeless?
 - How do you cope with this? What makes you feel more relaxed and happy?
- Ensure that each member gets a chance to speak if they want to.



STEP 3 Sharing information

10 mins

- Caregivers for people with mental illnesses face a heavy burden
- Caregiving for a family member is often founded on love and a sense of responsibility, but caregivers need resources and support to be able to keep up their caregiving
- Workers in other jobs get breaks, and caregivers also need breaks to maintain their physical and mental health
- One of the most important ways for caregivers to get a break is to ask for and accept help from people they trust
- Caregivers are not superhuman, they should not be too hard on themselves and expect themselves to do everything

- Caregivers need to do something that gives them enjoyment and peace, even if it's only a 10-minute break
- Stress, anxiety and depression are common in caregivers. They should watch for symptoms like thinking a lot, worry about lots of things at once, and being unable to stop worrying (anxiety), sad or "empty" mood, sleeping too much or too little, restlessness, irritability, loss of energy, feeling guilty, hopeless or worthless, thoughts of suicide or death
- If they are experiencing these they should seek help from a doctor, nurse, counsellor or psychologist.



STEP 4 Activity

10 mins

- Offering a friendly ear to listen to concerns and difficulties is an important way that caregivers can support each other. Ask caregivers if they can pair up and keep in contact to provide each other with support. They can start to talk today about practical ways they can do this.



STEP 5 End of session

5 mins

- Thank members for sharing their experiences and supporting each other
- This is the final session in the programme. Spend some time discussing how members feel and what they have gained
- Encourage them to continue to meet and support each other.

» Community Resource List

Organisation/Department	Contact number
Department of Housing	018 487 8588 018 487 8578 018 487 8577
Department of Labour	018 464 8700 018 464 8720
Department of Education	018 467 9300
Department of Health	018 487 8788
Department of Social Development <ul style="list-style-type: none"> • Victim empowerment program (VEP) • Substance program • HIV/AIDS • Disability Programme ○ TRIEST ○ Daphnee Lee ○ Techford ○ Huis Servaas 	018 462 5111 079 492 6041 082 522 1920 079 492 6181 071 681 0463 018 468 6741 018 462 4366 018 465 3631 018 468 4003
SASSA	018 487 2300
Department of Police	018 464 5080
Rehabilitation centers (Sanpark) Sanpark (drug and alcohol center) <ul style="list-style-type: none"> • Khulisa • Department of Health (School health) • Department of Health (School health) • New Destiny Foundation (Religious org.) • BOSASA • Love life (Matlosana youth center) 	018 462 4568/9 082 799 6831 018 464 4788/082 549 1319 018 464 2210/082 846 8484 018 464 2210/082 665 0716 083 723 5245/ 078 435 5163 082 856 0692 074 715 4749
Mental Health (Klerksdorp) Mental Health(Potchefstroom) NGO's involved in community work <ul style="list-style-type: none"> • Amelia (Potchefstroom) • Sixteen Steps (Ventersdorp) 	018 462 2598 018 297 5270 018 290 5543/018 297 0133/4 079 492 6220 018 264 3926/ 076 440 9278
Family Advocate	018 462 1611
Life Line	018 462 7838

Organisation/Department	Contact number	Contact name

Handout 1

My goals

My goal is to....	How will I achieve it?	How am I doing?

My thoughts and ideas

Handout 1

Maikaelelo a ka ke

Ke ikaelela go...	Ke tlile go dira jang se?	Ke dira jang?

Megopolo le dikakanyo tsa me

Handout 2

Coping with hearing voices

- Get to know the voices by keeping a diary, so that you know what seems to bring them on
- Accept that the voices belong to you, and are not an external force that can read your mind or steal your thoughts
- Realize that despite what the voices are saying, they are a part of you, so you are in charge, and no harm will come to you when you don't listen to them
- Do a relaxing activity such as gardening or listening to music when the voices come on
- Try different ways of quietening the voices, for example by humming when the voices come on
- Avoid unhelpful things such as arguing with the voices or using drugs or alcohol

Coping with Delusions or Unusual Thoughts

- Check your ideas of reality with a person you trust.

Handout 2

Ke kgona jang ka go utlwa mantswe

- Kwala mantswe a o a utlwang mo bukeng kana lekwalo la dikakanyo. Se se tka go thusa gore o a itse le go o itse gore a tlišwa ke eng
- Amogela gore mantswe a ke a gago, le gore ga a tswe ko ntle mo sengweng se se kgonang go bala tlhaloganyo ya gago kana sa utswa dikakanyo tsa gago
- Lemoga gore ntle le gore mantswe a a re eng, ke karolo ya gago, ka jalo o kgona go a laola, ebile ga go sepe se se maswe se se tla go diragalelang fa o sa a reetse
- Dira tiro ya boiketlo jaaka go lema tshingwana ya merogo kana go reetsa dipina fa mantswe a atla
- Leka ditsela tse di farologaneng go didimatsa mantswe a. Sekai nguna nguna pina fa mantswe a atla
- Tshabela dilo tse di sa thuseng jaaka go ngangisana le mantswe a kana go dirisa diritibatsi kana bojwala

Go kgona ditumelo tse di senang boammaruri kana dikakanyo tse di sa tlhwaelegang

- Lebelela gore a dikakanyo tsa gago ke boammaaruri le motho yo o motshepang

Handout 3

My medication information

1. What is the name of the medication I take?

2. How does it help me?

3. How and when do I take it?

4. What other instructions did the doctor give?

Handout 3

Kitso ka ditlhare tsame

1. Leina la ditlhare tse ke di tseyang ke eng?

2. Di nthusa jang?

3. Ke dinwa jaang, leng?

4. Ke taolo efe engwe e ngaka a e fileng?

Handout 4

Early warning signs

I Feel...	I Notice...	Others May Notice That...
<ul style="list-style-type: none"> • More tense • Depressed • Restless • Elated • Irritable • Afraid 	<ul style="list-style-type: none"> • It's hard to concentrate • I am forgetful • I find it hard to make decisions • I am thinking too much 	<ul style="list-style-type: none"> • I find it hard to sleep • I eat more or less than usual • I don't take care of my appearance • I am quiet • I am not interested in doing anything • I drink or use drugs

Things that can cause me to relapse...

- Not enough sleep
- Working too hard
- Stress
- Fighting with family
- Alcohol or drugs
- Menstrual cycle in women
- Not taking medication correctly

Handout 4

Matshwao a tlhagiso]

Ke ikutlwa...	Ke lemogile...	Batho ba lemogile gore...
<ul style="list-style-type: none"> • Ke gagametse thata • Ke na le kgatelelo maikutlo • Ke tlabatlaba • Go itumela go feta selekano • Ke tenega ka pele • Ke tshogile 	<ul style="list-style-type: none"> • Go thata gore ke beye kelelelo mo selong se le nosi ka nako e rileng • Ke lebala thata • Go thata gore ke tseye ditshwetso • Ke nagana ka thata/ ka 'touta' 	<ul style="list-style-type: none"> • Go thata gore ke robale • Ke ja thata kana ke fokoditse tsela e ke jang ka yone ya tlwaelo • Ga ke itlhokomele • Ke didimetse • Ga ke na kgatlhego mo go direng sepe • Ke dirisa bojwala kana diritibatsi

Dilo tse di ka dirang gore bolwetsi bo tsoge gape...

- Go sa nne le nako e e lekaneng ya boroko
- Go dira/bereka thata
- Go imelwa ke mathata kana stress
- Go lwana le ba leloko/losika
- Bojwala kana diritibatsi
- Go bona matsatsi mo basading
- Go sa nwe ditlhare sentle

Handout 5

Know yourself

1. I feel good about myself when...

2. When I think about the future I see myself...

3. I am good at...

4. I feel happy when...

5. I am grateful for...

Handout 5

Go ikitse

1. Ke ikutlwa ke itumeletse fa ke...

2. Ga ke nagana ka bokamoso ke ipona ke...

3. Ke kgona go...

4. Ke itumela fa ke:

5. Ke lebogela...



**Chapter 5: Paper 3: Community-based psychosocial rehabilitation
for schizophrenia service users in the North West Province of
South Africa: a formative study**

Community-based psychosocial rehabilitation for schizophrenia service users in the North West Province of South Africa: a formative study

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Keywords: schizophrenia, psychosocial rehabilitation, auxiliary social workers, low- and middle-income country, South Africa, task-sharing, acceptability, feasibility

Abstract

Background: Psychosocial support is recognized as important for recovery for service users with schizophrenia, in addition to provision of antipsychotic medication. This study aimed to develop a community-based psychosocial rehabilitation programme for service users with schizophrenia to be facilitated by auxiliary social workers, and investigate acceptability and feasibility of the programme.

Method: A task-sharing approach was adopted in which auxiliary social workers were trained to facilitate psychosocial rehabilitation groups. In-depth individual qualitative interviews were conducted with six group members at baseline, midpoint and endpoint (18 interviews in total). NVivo10 was used to store data and conduct qualitative framework analysis.

Results: Participants reported benefits of the programme including improvements in group members' self-esteem, social support, illness knowledge, self-care, and contribution to their

households. A key barrier to acceptability was the lack of provision of income generating opportunities. Implementation challenges include difficulties in tracing and engaging service users and families, lack of an appropriate venue, and issues with supply of antipsychotic medication.

Conclusion:

This study has provided evidence for the benefits and acceptability of this contextually adapted programme. Key barriers to implementation can be addressed through the provision of the necessary resources for auxiliary social worker input in the community.

Background

Schizophrenia can lead to great suffering for those affected and their families. The Global Burden of Disease 2010 study gave schizophrenia the highest disability weighting of all mental disorders studied (Whiteford et al., 2013). People living with schizophrenia require biomedical treatment to improve symptomatology and functioning, and psychosocial support to promote their individual journey of recovery (Anthony, 2003; Craig, 2006; Warner, 2009). There is a well-developed evidence base from high-income countries (HIC) for psychosocial approaches for schizophrenia, including psychoeducation (Pekkala & Merinder, 2002; Xia et al., 2011), family interventions (Pharoah et al., 2010), intensive case management (Dieterich et al., 2010), cognitive rehabilitation (McGrath & Hayes Robyn, 2000) and social skills training (Tungpunkom et al., 2012). Mutual support or peer support approaches, in which peers, or people further along in the recovery process act as resources or supports for others with schizophrenia, are also gaining momentum in HIC (Duckworth & Halpern, 2014; Mueser et al., 2013).

In low- and middle-income countries (LMIC) such as South Africa, community-based rehabilitation, psychoeducation and support for families (delivered by non-specialists) are

recommended (Mari et al., 2009). Psychoeducation interventions, which can be brief and inexpensive (Pekkala & Merinder, 2002), lend themselves particularly well to implementation in LMIC contexts and human resource constraints mean group interventions may be most feasible. Evidence for such approaches in LMIC remains limited, with a recent Cochrane review finding too few studies to draw conclusions on the benefits of non-specialist delivered interventions for schizophrenia (van Ginneken et al., 2013). However, supportive evidence (including non-randomised studies) with positive outcomes for group psychoeducation interventions for service users and for family and caregivers is accumulating from a variety of LMIC, for example China (Xiang et al., 1994; Zhang et al., 1998), the Czech republic (Motlova et al., 2004), Nigeria (Agara & Onibi, 2007), Chile (Gutiérrez-Maldonado et al., 2009), Iran (Fallahi Khoshknab et al., 2014; Karamlou et al., 2009) and India (Kulhara et al., 2009). Evidence is also growing for more complex multi-component approaches, including collaborative community care in India (Chatterjee et al., 2011; Chatterjee et al., 2014), community re-entry training in China (Xiang et al., 2007) and community care in Chile (Alvarado et al., 2012). In South Africa, recent studies have shown the potential for assertive community treatment (led by nurses and social workers) (Botha et al., 2014; Botha et al., 2010) and group-based family therapy (led by nurses) (Asmal et al., 2013). Peer support as a Facilitator of recovery has been the cornerstone of development of user-led mental health organisations in Africa (Kleintjes et al., 2013) and in the South African context where education levels, poverty and access to services are key challenges there is also a case for incorporating the concept of ‘guided peer support groups’ (Castelein et al., 2008) in which trained Facilitators guide the structure and content of groups initially, after which they become more user-led.

The combination of ‘older’, less expensive antipsychotic medication with psychosocial interventions delivered in a community-based service model is most cost-effective for treating schizophrenia in LMIC (Chisholm et al., 2008). The stark lack of resources directed towards psychosocial community-based services is well recognised in South Africa (Lund et al., 2010a; Lund et al., 2010b; Petersen & Lund, 2011). Although the Mental Health Care Act No. 17 of 2002 makes explicit the right of people with mental illness to rehabilitation services, lack of resources in relevant Government departments (Health and Social Development), as well as in non-governmental organisations (NGOs), mean these services are currently lacking in many parts of the country. Provision of psychosocial rehabilitation (PSR) for schizophrenia in collaboration with existing NGOs has been identified as a key challenge in the mental health landscape in South Africa (Lund et al., 2012a). Stabilized patients are discharged into the community for provision of chronic medication and monitoring at primary health care (PHC) clinics, but primary care staff are often not well equipped to provide the psychosocial support needed. Manualised psychosocial intervention packages using a task-sharing approach have been called for (Lund et al., 2012a).

There is currently little research in South Africa on the process of implementing community-based PSR programmes in conjunction with locally based NGOs. A situation analysis, including consultation with district stakeholders, in the site of the present study also revealed limited provision of community-based PSR (Hanlon et al., 2014). Assessing feasibility in implementation of health programmes incorporates several aspects of intervention delivery, including fidelity, acceptability, and how delivering agents and recipients perceive and react to the intervention (Bowen et al., 2009). This study aimed to develop a community-based PSR programme for service users with schizophrenia and conduct a formative evaluation to determine preliminary qualitative outcomes, acceptability and implementation challenges.

These are to be used to inform wider implementation and testing of the intervention, in line with MRC guidance for complex interventions (Craig et al., 2008).

Methods

This study is part of The PRogramme for Improving Mental health carE (PRIME), a research consortium implementing programmes for priority mental disorders in low resource settings (Lund et al., 2012b). PRIME in South Africa has worked to develop a Mental Health Care Plan for the Dr Kenneth Kaunda District, North West Province (Petersen et al., 2015). In conjunction with formative research on the experiences and perceptions of service users with schizophrenia in the district (Brooke-Sumner et al., 2014) this process led to the development of a programme of facilitated PSR groups for stabilized schizophrenia service users living in Dr Kenneth Kaunda District. A task-sharing approach was adopted whereby non-specialists [auxiliary social workers (ASWs) from the Department of Social Development and the provincial Mental Health Society, a NGO providing mental health services] would be trained to facilitate groups and refer service users to primary health care and specialist services where necessary in a stepped-care model.

Study site

The study site was determined in collaboration with the National Department of Health. Dr Kenneth Kaunda district is one of four districts in North West Province, with the entire province being 86% urban and 14% rural (Hanlon et al., 2014). The study involved service users from Majara Sepapho clinic, a PHC clinic servicing a population of 23 097 people in Kanana, a township on the outskirts of Klerksdorp, characterised by high levels of unemployment, poverty, social deprivation and high HIV prevalence (30%) (Hanlon et al., 2014).

Programme development

Formative work

The programme was informed by findings from qualitative research conducted with service users and caregivers in the district, reported elsewhere (Brooke-Sumner et al., 2014). Briefly, this indicated key areas of need to be (i) psychoeducation covering causes, symptoms, medication and adherence; (ii) skills-building, in particular managing anger, conflict and stress; (iii) promoting emotional well-being (iv) improving coping skills for dealing with stigma and discrimination, and (v) taking up productive or income generating activities. A systematic review of acceptability and feasibility of community-based psychosocial interventions for schizophrenia in LMIC generated approaches for improving acceptability and feasibility which were also incorporated into the programme (Brooke-Sumner et al., 2015).

Manualisation

Findings from formative work, a document review process, and consultation with a psychiatrist and psychiatric nurse providing PSR services in other provinces of South Africa informed a participatory learning-based training manual for a five-day training workshop for Facilitators of the programme (ASWs). A structured Facilitator Guide outlining the process for each group session was also developed. Main features of the programme are set out in Table 1.

Table 1: Outline of PRIME South Africa programme for psychosocial rehabilitation groups

Features of the programme	Description
Theoretical basis	Premised on WHO International Classification of Functioning, Disability and Health (ICF) (the biopsychosocial model) (King, 2007), addressing challenges faced by individuals in their social environment. Also draws on stress/vulnerability models (Yank et al., 1993) emphasizing building coping skills and building resilience.
Structure of the intervention	<p>Manual-based group sessions for service users (12 Sessions) and caregivers (5 Sessions)</p> <p>Service user sessions</p> <p>Session 1: Introduction to the Programme and Goal Setting Session 2: Understanding Our Schizophrenia Diagnosis Session 3 Understanding Medication Session 4 Income Generating Activities Session 5 Coping with Schizophrenia Session 6 Substance Abuse Session 7 Knowing Ourselves Session 8 Managing Anger, Stress and Conflict Session 9 Dealing With Stigma and Discrimination Session 10 Contributing to the Household Session 11 Money Management Session 12 Closure Session</p> <p>Caregiver sessions</p> <p>Session 1: Understanding Our Relative’s Illness Session 2 Coping with caring for a person with Schizophrenia Session 3 Family Conflict Session 4 Dealing with Stigma and Discrimination Session 5 Caring for the Caregiver</p>
Structure of the sessions	<p>All sessions followed a 5 step process:</p> <p>Step 1: Introduction and welcome, encourage participation and positive group norms Step 2: Sharing of experiences and group discussion Step 3: Sharing of information by Facilitator, structured psychoeducation Step 4: Activity integrating knowledge from session Step 5: Closure</p>
Tools for implementing the programme	<p>Training Manual for five-day training for Facilitators (ASWs) Facilitator Guide with background information, outline for each session and community resource list Referral forms for back-referral to PHC in cases of side effects, non-adherence, suicide risk Programme administration documentation for Facilitators (programme of session dates for group members, attendance lists, process notes form)</p>

Workforce, training and supervision

Identifying a sustainable workforce in the district to deliver the programme was a key challenge at the outset. The South African Ministry of Social Development Policy on Disability identifies the Department of Social Development (DOSD) as the primary role player with responsibility for provision of community-based services, promoting social integration and rehabilitation for people with mental disabilities (DOSD, Undated). This policy also highlights the importance of multisectoral collaboration. The research team conducted an intensive process of engagement with representatives from the Department of Social Development nationally and provincially, and with the South African Mental Health Federation, and their provincial arm, the North West Mental Health Society (MHS).

Each of these partners were in agreement on the need to provide the service and were supportive of involvement of ASWs and supervisors from their sectors. Fifteen trainees, including ASWs and social workers from DOSD and the MHS, as well as supervisors (disability coordinators and social workers) from DOSD were trained in September 2013. A Setswana-speaking clinical psychologist (OS) conducted the training with the first author. In an effort to promote ownership of the programme in the district, local service providers (occupational therapist, chronic care coordinator) were also involved in facilitating this training. Due to a lack of clear commitment of resources by DOSD, only two ASWs from the MHS were finally assigned to facilitate the programme. They had previous experience of working with clients with schizophrenia, mainly in assisting those who had a history of mismanagement of South African Social Services Agency (SASSA) disability grants.

Participants

Participants for the group were identified through review of clinic records at Majara Sepapho clinic. Criteria for inclusion in the study were a confirmed diagnosis of schizophrenia and being over the age of eighteen. Nineteen service users were identified. These service users were traced by community health workers who explained the programme and invited service users to the clinic for assessment. Ten of the service users were not found at the addresses indicated on their files and were not traceable. A functional assessment (incorporating a mini mental-status exam and assessment of cognition) by a clinical psychologist (OS) was carried out for nine service users who came to be assessed. Seven service users were referred to the group and two were excluded: one did not speak SeTswana (the language in which the group was to be conducted) and one had relapsed as was observed during assessment. He was referred to the clinic for further assessment and medication.

Implementation

Service user group sessions were conducted weekly over 12 weeks from October to December 2013. Sessions took place in the only available private space in the clinic, a security guard house at the clinic entrance. Efforts were made to identify a suitable space in the local community, but none was available. Caregivers were contacted through the service users and by home visits by ASWs, however only three caregivers attended the initial meeting and the caregiver group was not successfully formed. Reasons for this were investigated in the evaluation. A Setswana speaking supervisor, a qualified counsellor (Hons BA Psychology Degree) was present at eight sessions to check progress and fidelity with the programme manual, as well as to provide mentoring support to ASW Facilitators, in line with the apprenticeship model for task shared mental health interventions (Murray et al., 2011).

Data collection

In-depth individual qualitative interviews were conducted with group members at baseline, midpoint (six weeks after the start of the programme) and endpoint (18 interviews in total). The case series approach was employed to investigate, where possible, changes in member's knowledge, attitudes and experiences over time. Semi-structured qualitative interviews with the group Facilitators (two) and supervisor (one) were conducted at the end of the programme. All interviews and sessions were simultaneously translated into English and transcribed by a Setswana speaking Hons BA Pysch graduate. Interviews were done in a private room in the clinic and lasted an average of 45 minutes.

Data analysis

NVivo10 data analysis software was used to store qualitative data and conduct qualitative framework analysis. Individual interviews with group members and Facilitators were analysed thematically using a predefined coding scheme to capture themes and data under 'preliminary outcomes', 'acceptability' and 'implementation challenges'. The analysis approach also allowed for emergent themes particularly in the subjective reports of outcomes of the programme. The first author conducted the analysis process of familiarisation with the data through review, initial coding of data, identification of major themes and subthemes and refining of codes and themes until no new themes emerged (Lacey & Luff, 2001; Ritchie & Spencer, 1994). A triangulation process was used to bring together perspectives from Facilitators, supervisor and group members.

Ethical considerations

Permission was granted for this study from the University of KwaZulu-Natal and the University of Cape Town under the PRIME ethical approval (UKZN HSS/0623/012D; UCT HREC

412/2011). Service users' capacity to participate in the groups and give informed consent for research purposes was based on the functional assessment by the clinical psychologist (OS). Participants were advised of the voluntary nature of their participation and of their right to withdraw at any point. A detailed explanation of the research was given in Setswana at the start of the programme. All participants then provided written informed consent for participation in the groups and permission to report findings. An in-depth discussion on the importance of confidentiality to the group was also undertaken by group Facilitators, after which each member signed a confidentiality agreement. All personal identifying information was removed from the data and soft copies were stored on two password locked computers.

Results

Demographic data for group members are given in Table 2. There were two females in the group, and all group members were over the age of 45. All group members were unemployed and disability grants (approximately 108 USD per month at the time of the study) constituted the majority of household income for all but one member.

Table 2 Characteristics of service users attending PSR Programme

Group member	Age	Gender	Years since diagnosis	Comorbid conditions	Years of education	Employment status	Receiving disability grant	Household monthly income	Number in house-hold
1	54	F	7	Hypertension HIV	7	Unemployed	Y	R1260	2
2	48	M	18	Hypertension	9	Unemployed	Y	R1260	3
3	53	F	22	Epilepsy	6	Unemployed	N	R1550	4 (1 child)
4	62	M	Not known	Hypertension	Tertiary	Unemployed	Y	Unsure	6 (2 children)
5	53	M	3	None	6	Unemployed	Y	R1260	10 (3 children)
6	46	M	10	Hypertension	10	Unemployed	Y	Unsure	4
7	51	M	13	None	5	Unemployed	Y	R1800	4 (2 children)

Participation

Of the seven service users who attended the first group session, six attended the group regularly (each member missed only one or two sessions out of the twelve). One member only attended the first group and was lost to follow up thereafter. Several home visits were conducted by the Facilitators but he could not be located. Three caregivers came to the initial meeting to form the caregiver group. The remaining caregivers were reported to have jobs that meant they could not attend. One of the three caregivers suffered a stroke during the course of the programme.

Referrals

In the duration of the programme two members were referred to SASSA for reinstatement/administration of their grants. One member was referred back to PHC for a physical ailment, although it was noted by Facilitators that this was not appropriately addressed during the three month duration of the programme.

Qualitative data

Seven subthemes emerged within the major theme of preliminary outcomes (See Figure 1). Subthemes under the major theme of acceptability were enabling factors for acceptability (three subthemes) and barriers to acceptability (four subthemes). Data on implementation challenges provided four subthemes.

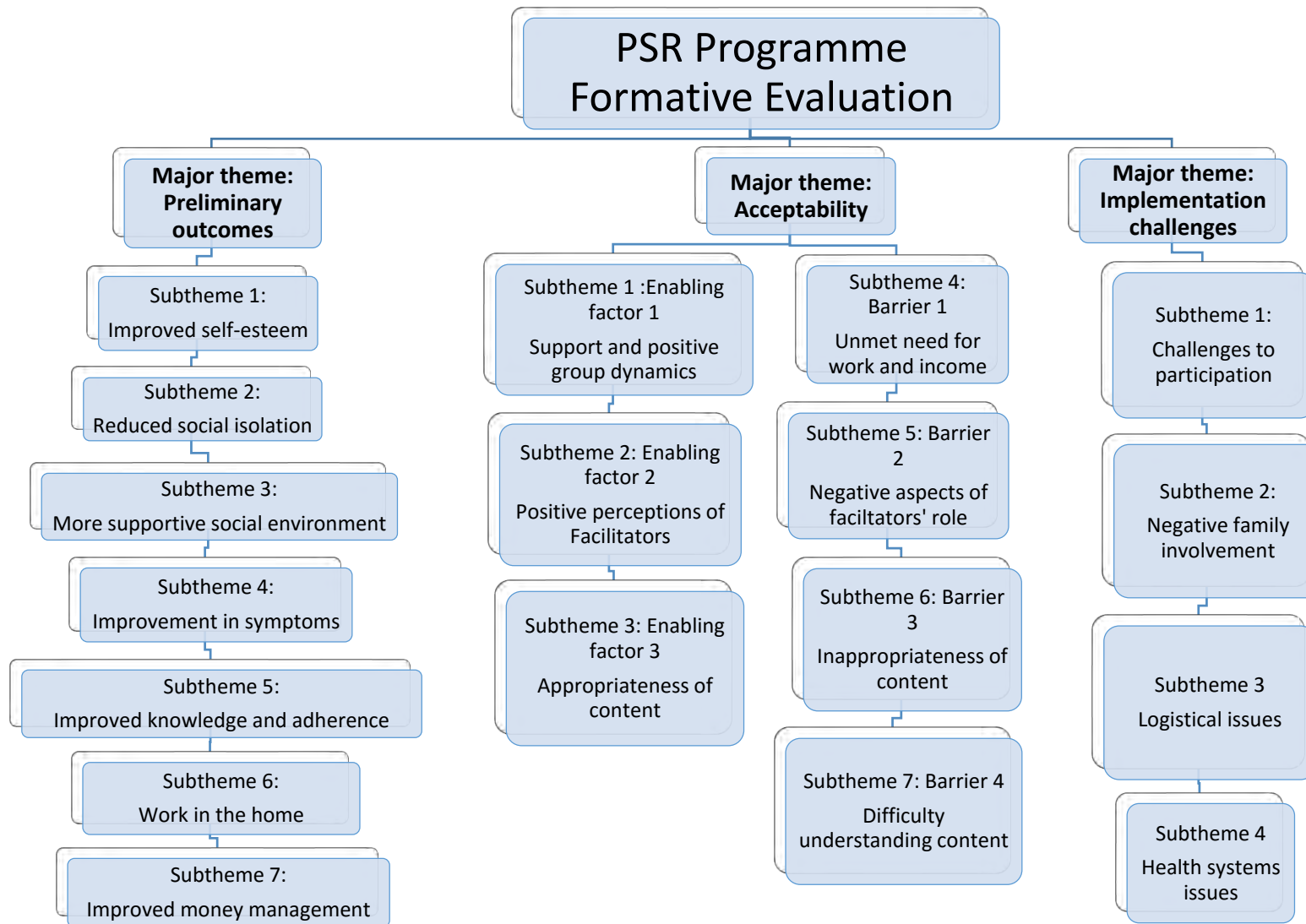


Figure 1. Diagrammatic representation of themes for formative evaluation of PRIME PSR programme

Major Theme: Preliminary outcomes

Both Facilitators articulated positive changes they saw in group members. They felt members gained knowledge on their illness and particularly they saw changes in practical aspects of members' lives (e.g., ability to contribute to household tasks, improved self-care).

'What I can say about [Group member] is that since he joined this group, he is happy, because it seems like at home he was just sitting and doing nothing. Even though he doesn't communicate as much as the others, it seems he is enjoying it' – Facilitator 2

Subtheme 1: Improved self-esteem

Members reported that being part of the group helped build their self-esteem and confidence. Being motivated to become more active (e.g., contributing to the household, gardening) and forming friendships improved the way some members felt about themselves. Two members reported seeing themselves as 'human' which they did not prior to the group and two members felt the group was their 'work' and they gained a new sense of pride in themselves from this. One member felt a sense of pride at having a 'support structure' around them.

'A lot has changed because before I didn't know myself but now I do. I'm a human being just like anyone else because I take my treatment correctly' – Group member 2

Group member 6: The support group has helped us do things for ourselves... it taught us that this illness does not mean the end...I've learned to be myself.

Interviewer: What would you say if someone asked you who [member's name] really is?

Patient: I would explain to that person that [member's name] is a good person who cares for other people – Group member 6

Subtheme 2: Reduced social isolation

Members recognised the group meetings as a valued opportunity for social interaction. One member felt the group had encouraged their family members to understand that they did not need to isolate themselves in the home and another expressed the ‘sense of belonging’ that the group had given him. Three members reported visiting each other at their homes. One member described how the group had given her the confidence to begin taking part in family activities that she had always been invited to, but that she had stopped going to because of fear of being mocked.

‘I was not a person that would visit others but now I do visit people and we can sit down and chat’ – Group member 5

Group member 3: They've [family] always invited me but I was the one who wasn't interested because I didn't like their way of doing things, like poking their heads to show that I'm crazy.

Interviewer: But what do you think has changed for them to treat you better?

Group member 3: I think it's the support from the group that has encouraged me to accept what they were doing.

Subtheme 3: More supportive social environment

At baseline, the majority of members reported experiences of stigma and discrimination from family, friends and community, including being taken advantage of (e.g., through giving friends loans from their disability grant that were never paid back), being rejected by possible part-time employers due to their illness, and being mocked at social events.

‘In the community I played a role, I attended funerals but now I cannot because I am a joke to people. People see me as a joke, you would see them poking each other, talking

saying that she is crazy. I see them just as people, if something happens I could help, but they see me as a crazy person.’ Group member 3

While the majority of group members indicated at baseline that they felt their families were supportive of them, the majority also reported that being part of the group had led to them being treated better by family members (who had a better understanding of the illness), community members or clinic staff. They described family members being more supportive and taking better care of them (e.g., making food, reminding them to take medication). Two members described how they shared with family members what was covered at group meetings and that they believed this was the reason for the improved levels of support.

Interviewer: Since you started attending the support group have you seen changes in the way she [family member] treats you?

Group member 4: Yes, she is lenient... she has patience for me. She wakes up in the morning to fix me a bath.

‘Right now I see changes as people [community members] talk to us properly. The people in the community who came to the clinic they did not treat us well...they looked at us as nobodies in the clinic. Yesterday I was called [by a community member] in the clinic to come take my medication because I was still in the line’ Group member 3

Facilitators however noted a contradiction in that although group members reported that family members treated them well, when the Facilitators visited their homes during the course of the programme, they found some lived in outbuildings and noted mistreatment by families.

Subtheme 4: Improvement in symptoms

While all group members linked improvements in symptoms to their medication, and most recognised the group as supporting their adherence, one member explained that she believed the group itself had had a positive impact on her symptoms, causing a reduction in headaches.

Group member 3: I have seen changes as I don't have headaches that much anymore, it is not every day but sometimes, or I have headaches sometimes but at least I still sleep well.

Interviewer: How do you think the support group helped in making those changes?

Group member 3: It helps in that I can think now, my mind is not thinking about one thing only, I can think of many things...I am happy that I am not alone I used to think I was alone.

Subtheme 5: Improved knowledge and adherence

Only one group member knew the name of their diagnosis at baseline, having looked it up in a dictionary (as it was not explained by their health professional). However all group members were aware of the symptoms and chronic nature of their illness. They all also reported adhering well to their medication and although they expressed little knowledge of the names of their pills, three correctly named their injectable medication (Modecate). They placed great value on the benefits of medication and the changes it brought to their lives and were aware of specific directions for taking their medication. Challenges to adherence (e.g., forgetfulness, poor living conditions) were noted.

When I take my pills and injections I am just like anyone else, but if I do not get the injection or take my pills there is a difference. When I am sleeping at times I dream

strange things so I have to take my pills and if I miss a day.... whenever I forget to take them in the evening I feel that I am not OK - Group member 2

Although some group members still struggled to remember the name of their diagnosis after being part of the programme, every group member reported that the group had encouraged them to adhere to their medication, understand their illness better, and make the link between not taking medication and the risk for relapse. One member explained that their family did not need to remind her to take medication any more, she always remembered herself. The majority of group members also reported gaining knowledge on the risks of substance abuse and two reported to have reduced or stopped drinking alcohol. Two members however remained resistant to the idea of stopping smoking or using snuff.

'It [group] taught me to know myself and understand what I'm doing. I learned that I should always take my medication...that I must never forget that because I will relapse'
– Group member 1

Subtheme 6: Work in the home

In line with Facilitators' reports, the majority of group members described helping more with household chores including cooking, cleaning, laundry, looking after children, clearing the yard and gardening. Two male members said they started contributing in this way after being part of the group, which they recognised they did not do previously. One male member however remained resistant to any household work with the expectation that his female caregiver should do this work.

Group member 5: Before if someone asked me to help I would be lazy, I would not help them [family]. They would shout at me asking me to help them and saying that I should not be lazy

Interviewer: Which work was difficult for you to do that is easier now?

Group member 5: Washing the dishes was difficult, I would refuse to wash them and I would ask them [family] why they don't wash the dishes themselves...but now I wash them.

Subtheme 7: Money management

Half of group members felt being part of the group had encouraged them to budget more effectively and to save part of their grant where possible.

'I don't waste my money anymore. Since the support group has started I bring my grant as it is to the house and give it to them [family]. I don't spend it on alcohol anymore'.

Group member 2

Major theme: Acceptability

Subtheme 1: Enabling factor 1: Positive group dynamics and sense of support

Most group members spoke of the benefits they felt from getting to know each other and feeling at ease in the group, particularly in gaining support and comfort from other group members as well as the Facilitators.

In our group we now know each other as we did not know each other at first. We can understand if one of us is a certain way, we know why they are like that. When we are together we can say 'this one's weakness is this, today he/she is not well we can see it'

– Group member 3

Subtheme 2: Enabling factor 2: Positive perceptions of Facilitators

The majority of members had positive views of the Facilitators and articulated how they had helped them. Most recognised the 'teaching' role that the Facilitators had in sharing information about coping with the illness. Members also valued their role as social workers,

helping with accessing grants and medication. The fact that the Facilitators treated group members with respect and not as ‘mentally ill’ was also recognised. Most members felt that the Facilitators were well informed and prepared and the benefit of having two Facilitators who each bring something unique to the group was recognized.

‘[The benefit] is the comfort they are giving us. They tell us to be persistent and not to give up. They also help us obtain our medication and provide information’. – Group member 2

Group member 3: I found out from the support group about the disability grant from the state.

Interviewer: Oh you heard from [Facilitators] because yours was cut last year?

Group member 3: Yes. Because every time when I book an appointment [with SASSA doctor] they would always say it’s full. So I gave up.

Interviewer: So now what pushed you to go back?

Group member 3: [Facilitator] took me to the doctor.

Interviewer: Oh she walked you inside the doctor’s room?

Group member 3: Yes, she did that and made an appointment for me.

Facilitators noted positive aspects of how they performed their roles, through encouraging communication particularly by speaking clearly, repeating information if necessary and checking that group members understood what they were speaking about, as well as encouraging all members to participate. They also reported encouraging members in the face of difficult experiences, particularly mistreatment from family.

'At the sessions everybody was participating because I asked them one by one what is this and what is that and how do you feel. I gave them all the chance to talk'. – Facilitator 1

Subtheme 3: Enabling factor 3: Appropriateness of content

Sessions commonly cited as being most liked or most helpful were 'Knowing Ourselves', 'Managing Anger and Conflict', 'Substance Abuse', 'Income Generating Activities' and 'Contributing to the Household'.

Interviewer: Which one did you find it as most helpful and valid to yourself?

Group member 2: The drug one

Interviewer: Why do think that it was the most helpful?

Group member 2: Because I didn't know about all of this... that smoking marijuana, it's really true that we aren't supposed to smoke it.

Facilitators felt the session topics were appropriate, except for the money management session as it was noted that many service users do not control the money from their disability grants, this is up to family members. The supervisor also noted that group members had other health issues and take chronic medications other than antipsychotics and time should be given for them to discuss these.

'The Facilitator would ask, 'how do you take your medication? Do you follow what the doctor said?' The focus would be on the schizophrenia medication. And I think that it could have been easily missed that some of them are taking other medication as well for high blood [pressure], for epilepsy' – Supervisor

Both Facilitators found the structured format of the intervention acceptable and felt their training and the Facilitator Guide were sufficient for running the group sessions. One Facilitator did report anxiety about the role initially. Both Facilitators felt they had an advantage in having worked with schizophrenia service users previously. They felt the role would be challenging for someone without this previous experience.

'When we did the training it was a little bit scary because we didn't know what we were going to need in the field. But when we started to do it [groups] we found it's something very easy and interesting to do. I was thankful because we were working with stable patients'. Facilitator 1

Subtheme 4: Barrier 1: Unmet need for work and income

At baseline, the majority of group members expressed the desire to be able to work and gain an income. One group member also wanted to study further, and to help children in his community. None of the group members were officially employed but the two female members looked after their respective grandchildren and one had permanently adopted her grandchild. After the programme, one member emphasized that the groups should provide more than a chance to meet and gain knowledge and support, but also the possibility for employment or to engage in a specific income generating activity. Half of the members indicated that the session on income generating activities had made an impression on them and they wanted to supplement their grant, but by the end of the programme none were able to take forward a plan for doing so.

'I do not have a plan to earn money, I just watch television' – Group member 5

Group member 3: As I do not have a job I wish that they [Facilitators] could talk about working, if they could find a job for me that would make me happy

Interviewer: But do you remember when the group started they said the group is not about finding you a job, they cannot give you medication or money

Group member 3: Yes, but they could help me do something to help me make money, to do something with our hands, maybe to sell something.

Subtheme 5: Barrier 2: Negative aspects of Facilitators' role

One group member expressed a negative perception of the Facilitators, saying that they didn't seem confident and organised. The supervisor felt that the level of information giving may have led to less time spent on sharing experiences. One Facilitator also alluded to a pattern that developed between the two Facilitators in which one was more confident and outspoken leading to the other Facilitator feeling undermined. By the end of the programme both Facilitators felt they could facilitate the groups alone and seemed to prefer this option.

'It is a good thing to inform the patients, and they have better knowledge of their illnesses. But at the same time, with certain sessions, I felt that the patients didn't have enough chance to share their own experiences...- Supervisor

I think that if there are [two Facilitators] it can be damaging if one says "no it's not like that, it's like this" in front of the people [members]. I think if I can have my own [group], I will explain things better... – Facilitator 2

Subtheme 6: Barrier 3: Inappropriateness of content

One group member said there should be no task or 'homework' as it became known, although two specifically said they were happy with the tasks associated with the sessions. Two group members expressed a desire to do something practical other than just talking as a group (e.g., sewing, handcraft). Although each member was asked for changes that could be made to the programme or sessions that were least liked, only three members responded to this question –

one saying that he did not enjoy the session on ‘Knowing Ourselves’ as he felt he already knew himself, and another who did not enjoy session on ‘Stigma and Discrimination’ as he did not like talking about the way poor treatment by others affected them. Another member felt there could have been more discussion on whether group members could be ‘cured.’

Subtheme 7: Barrier 4: Difficulty understanding content

Two members said they had difficulty understanding the content of sessions. One attributed this to his being confused and stressed due to his illness. The other found one of the Facilitators’ language difficult to understand.

Group member 3: Sometimes we didn't understand, and we would just keep quiet because we were scared to clarify things. Rather we [group members] would discuss it in our own way. And we would ask each other what the Facilitator actually meant.

Interviewer: Did you feel that the Facilitators were rude, what made you scared to clarify things?

Group member 3: No. We didn't understand because [Facilitator's] Setswana was a bit different and it was difficult to understand.

Interviewer: Ok. But eventually did you understand everything?

Group member 3: Yes

Major theme: Implementation challenges

Subtheme 1: Challenges to participation

The most common reasons group members gave for non-attendance were funerals and other family commitments. One group member thought that others did not take the group seriously enough or that they were discouraged from attending because their family did not appreciate the importance of group meetings.

Group member 6: They [other group members] think that we are playing here...sometimes they are influenced by people, then they get discouraged.

Interviewer: Why do you think that they see this group as a play-play thing?

Group member 6: I see it when we talk to them, and even for me, at home when I tell them about the group, my sister does not know that this is important.

Facilitators also believed that some caregivers were not supportive of service users attending meetings (e.g., did not prepare food for them in time for them to leave the house). They also noted that some members struggled to remember meeting times, and one Facilitator felt that caregivers would not want to accompany their family member to the clinic because of stigma.

Before we start the group we have to start with the family first and tell them why we want the patients. So that when we start with the patients, already the family knows why the patients have to go there [to group meeting]. – Facilitator 1

Subtheme 2: Negative family involvement

Despite the common reports at baseline of the support of families, some members did report mistreatment by families, for example through restriction of their activities.

They don't ever want me going anywhere. When I try to exercise my legs they don't want me to do that, they want me in bed at a certain time, I even asked them how long I will be a prisoner at the house..... Group member 6

During and after implementation of the programme the majority of group members noted challenges in their family environment that could affect their ability to participate in or benefit from the programme. One member whose son also suffered from a mental illness reported that he refused to take medication and used drugs and alcohol. Another reported that his caregiver had started abusing alcohol heavily, and a third felt that their family members still did not

understand the illness and that they only paid any attention to her when she was behaving strangely. One member also said that their caregiver who controlled their grant money had refused to give him 'pocket money' since he had been part of the group. Conversely, one group member indicated how his own behaviour may have been causing conflict in the family in that he refused to be involved in any household tasks. Facilitators also felt that families could be a barrier to members' participation in the programme and that they should be engaged with before the start of the programme.

'I think the family they have to be supportive of what they will be doing [income generating project]. Because in the project that we spoke about, we spoke about gardening. And the thing is, some families they will think that they [service user] are just wasting water, that they don't know what they are doing'. – Facilitator 1

Subtheme 3: Logistical issues

All group members were able to walk to the clinic for group meetings. One said he lived relatively far but did not mind the walk. One walked an hour and a half to get there and felt that this was a challenge to his participation, and another said he felt very tired after the walk. All members expressed dissatisfaction at the venue and that this impacted on the experience of the group meetings.

I would have a proper place for us to meet, one in which we could work, not this one that belongs to the security guard. It would be place [for us] to work, it would be my office – Group member 5

'It [venue] doesn't seem good at all. ... if we could have a building for all patients, so that we connect with each other and our own garden place where we would do our own special gardening'. Group member 3

The challenge of finding a suitable venue was noted also by Facilitators before the programme roll out. The supervisor also reported that for some sessions they had to meet with group members outside which was not conducive to positive group work.

'On the days that we were there [outside the clinic], I think it was the post-natal day, and you had little kids running around. You would have them walking up and down all the time and calling the other ones, screaming. And that obviously affects the group dynamic and the patients' concentration'. - Supervisor

Subtheme 4: Health systems issues

At baseline one member reported difficulty gaining access to support needed to deal effectively with medication side effects, having been told by a nurse that she would have to wait a month for an appointment with the doctor to address severe headaches. During implementation, one member expressed dissatisfaction at the integration of mental health patients into PHC. However two other members did not feel that being integrated with other patients had a negative impact.

'I wish that we would be given a day that we come so that we do not go inside there [clinic]. We should get our medication here [support group]. Because inside there we are mixed with hypertension, diabetes patients... all these illness. We wait for a long time' – Group member 3

Two group members described having run out of medication and having difficulty in accessing medication, with both noticing negative effects on the control of their symptoms. One explained how he coped with this situation by 'sharing' medication with another group member.

Group member 2: They [clinic staff] said my script has left on Monday, so I'll start to get my pills again soon

Interviewer: So did they say when you are going to get your medication?

Group member 2: By next Thursday

Interviewer: So you haven't had your medication for a while?

Group member 2: No

Interviewer: But how do you feel?

Group member 2: I don't feel alright. And I've noticed that my flesh is shaking.

Interviewer: So are your pills finished at home?

Group member 2: Yes they are finished but I went to fetch some from [Group member] which are similar to mine so I can take them while I'm waiting.

Facilitators also recognised the inadequacies in the provision of chronic medication to group members. One Facilitator noted a change in behaviour of one of the members since the start of the group as he became quiet and isolated when he did not have his medication. This issue with medication was reported by Facilitators to be common for clients of this particular clinic.

'He [group member] was supposed to get his medication sometime in November. And now its December, he still hasn't got his medication. Even when we had the sessions we would see him and he would say 'no, I'm here for my treatment, but it hasn't been costed yet.' - Supervisor

Discussion

This formative study aimed to assess the process of implementing a programme of PSR for people with schizophrenia through a qualitative assessment of preliminary outcomes, acceptability and implementation challenges. It adds to the limited evidence on task-sharing interventions for schizophrenia in LMIC and builds on existing literature showing task-sharing interventions to be generally feasible and acceptable to service users and providers

(Padmanathan & De Silva, 2013). In particular it adds to task sharing evidence, showing ASWs to be an appropriate cadre to facilitate this type of intervention.

Positive outcomes as reported by group members and Facilitators emerged prominently from the data. This correlates with the strong levels of participation in the group over time, even though the number of participants was small. Service providers reported improvements from baseline in terms of group members' illness knowledge, self-care, reduced social isolation and contribution to their households. Group members themselves identified improvements in all of these areas over time, and also reported improvements in their self-esteem and sense of support in their social environment. These perspectives underscore the relevance of the qualitative formative research which informed the development of the intervention, the need for which has become well acknowledged (Padmanathan & De Silva, 2013; Patel et al., 2011). A further consideration is that participants were all older than the usual age of first episode psychosis (where PSR interventions are usually indicated). It could therefore be possible that a wider range of positive outcomes, and stronger evidence of positive effect of the intervention could be seen with a younger group of participants in further implementation of the intervention.

While the triangulation approach employed in the analysis indicated that group members' and Facilitators' perspectives on benefits of the programme were mostly well aligned, there were some differences of opinion. For example service users cited improved money management as a benefit, whereas one Facilitator felt that the session covering this topic was not appropriate as group members had limited control over their financial resources. In this study there was no evidence of family members taking advantage of grant money over which they had control, in contrast to evidence of this in a previous study in the district (Brooke-Sumner et al., 2014).

However this may reflect a lack of disclosure by group members, similar to the contradiction raised by Facilitators who reported mistreatment by family members even though group members did not report this themselves. This highlights the significance of the programme engaging meaningfully with individual families as a core aspect of the programme, and for ASW time to be allocated appropriately to these tasks, which will require a greater input of resources.

In relation to acceptability, group members generally had positive perceptions of the Facilitators, suggesting the acceptability of service delivery by non-specialists (ASWs). This is in line with positive perceptions of non-specialists in other LMIC mental health interventions (Padmanathan & De Silva, 2013). Personal characteristics of Facilitators were a key enabler of acceptability. These factors, as well as language competency and education level were also identified as promoting acceptability in a systematic review of psychosocial interventions for schizophrenia in LMIC (Brooke-Sumner et al., 2015).

Barriers to acceptability emerged which can inform the refining of the programme. Although the content and format of the programme were generally acceptable, the inclusion of any reading or writing task should be reconsidered as this did seem to raise levels of discomfort for some. While limited data were generated on what group members thought could be specific changes to the programme content, one session (Knowing Ourselves) emerged as most liked and also least liked by members. This highlights the tension of having a standardised, group based intervention aiming to support the recovery process, which is unique to the individual. Some members' difficulty understanding the content and language in the sessions could be addressed by further simplification of session content and training of Facilitators on effective

communication specific to mental health issues. While the Facilitators were first language Setswana speakers, they needed to develop the language for speaking about schizophrenia in Setswana, previously mainly done in English. Some group members viewed Facilitators as being unprepared, and this may relate to the fact that this role was in addition to their full time role within the Mental Health Society. While this was negotiated with the organisation prior to the programme, Facilitators reported that the programme took more time than planned as they followed up members with home visits. The conflicting demands on lay workers time in task-sharing models is a challenge highlighted in a recent report of acceptability and feasibility of task-sharing interventions for mental health in five LMIC (Mendenhall et al., 2014). One possible solution implied would be a more clear description of roles and responsibilities, and linking these to the process of supportive supervision (Balaji et al., 2012), promoting increased recognition and support from the employing organisation (Mendenhall et al., 2014). One service provider reported anxiety around their role, in line with findings from previous studies that suggested distress associated with task-shared roles (Padmanathan & De Silva, 2013; Petersen et al., 2011). The slight tension that developed between the Facilitators may also indicate some insecurity felt in relation to the role. Training and supervision could be strengthened in the programme to address these issues (Mendenhall et al., 2014; Padmanathan & De Silva, 2013). Refining training to enable ASWs to fully appreciate the value of sharing experiences as opposed to simply sharing information in the group is also indicated.

A key barrier to acceptability was that the need for productive activity and employment that emerged in the formative work, at baseline and throughout the programme delivery, was not specifically met by the programme. Although the session on income generating activities was designed to initiate discussion around a member-directed activity, an income generating project was not undertaken by the end of the programme. The evidence suggests a need for more

structured support and linking groups with community development projects, in line with the experience of the Basic Needs model for integrating mental health and development (Raja et al., 2012), which requires longer term input.

This study has brought to light several important challenges to implementation of the programme. The most commonly reported barrier was the lack of an appropriate venue in the community. Such logistical factors are important impediments to the feasibility of task-sharing interventions in LMIC (Mendenhall et al., 2014) and reflect the broader challenges of providing services in low resource environments. Group members and service providers in this study also confirmed difficulties in accessing medication in PHC. Previous studies in South Africa have recognised this situation as a crucial impediment to adherence (Breen et al., 2007) and have highlighted too few staff with little training on mental health, inadequate records and poor referral and communication between levels of the health system as underlying causes (van Deventer et al., 2009). Investigating and addressing the medication supply challenges in this context will be a crucial step in promoting the feasibility of the programme. The negative role family members may play would need to be addressed in wider implementation through earlier and more intensive engagement with families. Three further implementation challenges were faced. First, it was difficult for the project team to trace service users and engage them in the programme, which led to a small number of members in the group. Reasons for this included out of date contact details on clinic files. There were also anecdotal reports of high numbers of treatment defaulters who had not had contact with the health system for some time. A vital enabling factor for participation in the South African context is having multiple contact numbers and being able to do follow up home visits (Petersen et al., 2014) which in this case relies on the quality of clinic records. Second, due to a small number of attending caregivers, the caregiver group was not formed. Reasons for low levels of attendance were caregivers being

employed, being unable to walk to the clinic due to illness and lack of clear information on the groups. One Facilitator also felt some family members were reluctant to come to the clinic with group members due to the fear of stigma, which corresponds to the experience of other interventions for schizophrenia in LMIC (Balaji et al., 2012). More extensive mobilisation and engagement, requiring additional inputs of ASW time, are indicated. Third, although a supervision plan was put in place, the supervisor (social worker from MHS) left the organisation during the implementation of the programme and was unable to fulfil their role. Staff turnover is recognised as a challenge to the provision of high quality supervision and support required in the well-established apprenticeship model for task-sharing mental health interventions (Murray et al., 2011). Overall, provision of adequate resources for the programme is a major underlying challenge. Better resourcing of the programme (e.g., through allocation of more ASWs, or more ASW time) would enable them to i) conduct more extensive community and family engagement before the start of the programme; ii) facilitate groups for a longer period of time, allowing focus on an income generating project.

Limitations

A key limitation of the intervention on which this study is based is that it does not address the identified comorbidities of group participants. This would need to be addressed in further implementation. The study has fulfilled a key role of a formative study by identifying ‘uncertainties’ that will affect its wider implementation (Craig et al., 2008). There are however several limitations in terms of the data on which the study was based. The small numbers of interviewees (both group members and Facilitators) could have introduced a bias in terms of perceptions of the programme. The positive outcomes reported are subjective and qualitative and could have been biased by a desirability response. In further study of the programme objective and standardised indicators should be assessed (e.g., symptoms, functioning). A

further potential bias was that Facilitators were currently working in a mental health organisation, were committed to working with those with mental illness and may have had a more positive view of the programme than other non-specialists would have. Some group members were more communicative in interviews than others, so the data for these members was richer and relied on more heavily in the analysis.

Conclusion

This formative study has provided evidence for positive preliminary outcomes and acceptability of this contextually adapted programme for PSR for stabilized schizophrenia service users. The benefits reported by service users and providers suggest the programme warrants further investigation on a larger scale using quantitative objective measures of symptoms and disability. Key implementation challenges will need to be addressed through the provision of the necessary resources for these service users in the community. While task-sharing interventions can be cost effective, more resources are still needed for their sustainable provision (Padmanathan & De Silva, 2013), particularly in contexts such as the current study in which no PSR delivery platform exists at present. The provision of these resources will require effective intersectoral collaboration between the Departments of Social Development, Health, and community organisations (Petersen, Lund, & Stein, 2011).

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Competing interests

The authors declare that they have no financial or personal relationship(s) that may have inappropriately influenced them in writing this article.

Author contributions

CBS developed the intervention manual, co-facilitated training, conducted analysis, and prepared first through final drafts. IP contributed to the intervention manual, provided overall management for the research process, advised on analysis, and reviewed first through final drafts. CL contributed to the intervention manual, advised on analysis, and reviewed first through final drafts. OS reviewed the intervention manual, managed participant recruitment and other research processes on site, co-facilitated training, conducted functional assessment and research measures, and reviewed first through final drafts.

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Chapter 6: Paper 4: Bridging the gap: investigating challenges and way forward for intersectoral provision of psychosocial rehabilitation in South Africa

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Bridging the gap: investigating challenges and way forward for intersectoral provision of psychosocial rehabilitation in South Africa

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Abstract

Background: Intersectoral collaboration between government sectors such as Health and Social Development and non-governmental organisations (NGOs) in communities is crucial for provision of psychosocial rehabilitation (PSR) for those with severe mental illness. This study aims provide recommendations for strengthening such intersectoral collaboration in South Africa and with relevance to other African and low and middle income countries.

Methods: Twenty-four in-depth semi-structured interviews were conducted with 16 key informants from the South African Department of Health, 2 key informants from the Department of Social Development, 4 key informants from the NGO sector and

one key informant from a service user organisation at national level. Framework analysis was conducted with NVivo 10 software.

Results: Challenges to intersectoral work identified were lack of communication between sectors, problems delineating roles, and each sector's perception of lack of support from other sectors. Participant-identified strategies for addressing these challenges included improving communication between sectors, promoting leadership from all levels and formalising intersectoral relationships through appropriate written agreements; as well as ensuring that what resources are available for PSR are effectively re-directed to district level.

Conclusion: This study has outlined several directions for progress to address challenges for intersectoral working for PSR in South Africa. These may be of relevance to other African and low and middle income countries. Political will and a long-term view will be necessary to realise these strategies.

Keywords

Intersectoral collaboration, partnerships, psychosocial rehabilitation, severe mental illness, community-based rehabilitation, community development, mental health policy

List of abbreviations

AIHP	All India Institute of Hygiene and Public Health
BREC	Biomedical Research Ethics Committee
CAPS	Centers of Psychosocial Care
COREQ	Consolidated Criteria for Reporting Qualitative Research
DOH	Department of Health
DOSD	Department of Social Development
HIC	High Income Country
ICDM	Integrated Chronic Disease Management
LMIC	Low and Middle Income Country
NGO	Non-Governmental Organisation
PRIME	Programme for Improving Mental Health Care
PSR	Psychosocial Rehabilitation
SASSA	South African Social Services Agency
SHIP	Sonagachi HIV/AIDS International Project

Background

WHO defines 'intersectoral action for health' as a relationship between the health sector and other sectors which is necessary to improve health outcomes more effectively, efficiently or sustainably than would be achieved by the sole action of the health sector (WHO, 1997). The need for intersectoral collaboration in the provision of comprehensive community-based mental health services is well recognised internationally and in South Africa (Bhana et al., 2010a; Petersen & Lund, 2011; Petersen et al., 2011; Saraceno et al., 2007a; Skeen et al., 2010; Thornicroft et al., 2010a). The WHO Mental Health Action Plan 2013-2020 also cites a main objective of improving provision of integrated mental health and social care services in communities (Saxena et al., 2014).

Intersectoral collaboration is crucial, particularly for provision of psychosocial rehabilitation (PSR) for those with severe mental illness (a mental disorder meeting diagnostic criteria and causing serious functional impairment). These individuals are recognized as having a range of medical and psychosocial needs (Jenkins et al., 2011) whether they are hospitalised or living in the community. The potential benefits of an intersectoral approach are well accepted and in High Income Countries (HIC) intersectoral work is mandated for a range of health and social services (Darlington & Feeney, 2008). For example, models of Assertive Community Treatment and more recently Intensive Case Management involve multidisciplinary specialist community-

based teams (comprising psychiatrists, nurses, social workers, psychologists, occupational therapists and others) (Bond, 2001; Dieterich et al., 2010a) and rely on partnerships with service users, families and local community services, including social welfare and housing sectors (Alem et al., 2008). The human resource crisis for mental health in many low and middle income countries (LMIC) currently precludes the feasibility of a community-based specialist team for PSR. Provision of adequate long-term care in the community in LMIC, within the real-world resource-constrained context, will however of necessity require collaboration between the relevant government and non-government sectors.

In the African context although some countries have policies on development of community-based services, actual implementation of these policies has proved challenging (Hanlon et al., 2010). One reason for this in South Africa (DOH, 2013), as internationally (Saraceno et al., 2007b), is rapid progress in down-sizing of specialist psychiatric hospitals that has not been accompanied by the recommended ring-fencing of money saved for direction to community-based services (Petersen & Lund, 2011; Thornicroft et al., 2010a). As in some HICs in the past, the process of deinstitutionalisation in South Africa in particular has been viewed as an opportunity to cut mental health budgets (Petersen et al., 2011) and the overall low level of resources for psychosocial community-based services persists (Coetzee & Kemp, 1982; Lund et al., 2010a; Lund et al., 2010b; Petersen & Lund, 2011). This challenge may be compounded by lack of skills on the part of managers and those implementing policy

to advocate for resource allocation for community-based services in the milieu of competing health and mental health priorities (Jenkins et al., 2011), a challenge that may not be limited to South Africa or other LMIC settings.

Similar to the situation in other LMIC, there are therefore important gaps in the provision of PSR services in South Africa, particularly in rural areas (Petersen & Lund, 2011). The Government Health and Social Development sectors are clearly mandated in national policy for provision of PSR. Current levels of service provision however vary widely across provinces, with the National Department of Health (DOH) remaining focused on a biomedical treatment model and the National Department of Social Development (DOSD) activities being limited to provision of disability grants and funding of non-governmental organisations (NGOs). As in other LMIC, current service provision for PSR in South Africa thus continues to be mainly through NGOs (Petersen et al., 2011) (e.g. South African Federation for Mental Health). These NGOs are partially funded by DOSD to provide this service, under the DOSD Policy on Disability (*Ministry of Social Development: Policy on Disability*, Ministry of Social Development). Since DOH is not routinely funding NGOs in a similar way for provision of PSR services, the question remains as to what extent savings resulting from deinstitutionalisation are following patients into the community (Petersen et al., 2011; Thornicroft et al., 2010b). Experience of PSR in LMIC indicates NGOs are typically limited in their ability to provide sustainable services. NGOs in middle

income countries particularly may find it challenging to secure sustainable donor funding. The failure to fully integrate NGO services with those provided by government Health and Welfare sectors to ensure continuity of care and provision of the full range of services required also challenges sustainability and limits the quality of care provided (Rangaswamy & Sujit, 2012).

Addressing the PSR service gap is a key challenge in South Africa (Lund et al., 2012) and other LMIC. Notably in South Africa this service is urgently needed to reduce the revolving door phenomenon (repeated discharge into the community followed by rehospitalisation) and high numbers of individuals with severe mental illness being homeless or living in prisons (DOH, 2013). Within the health sector in South Africa, there is limited care for those with severe mental illness in primary care except for symptom management through the provision of ongoing antipsychotic medication. Lack of capacity at this level for medication management, poor links with other levels of the health system and supply chain issues are however known to lead to inconsistency in the availability of medications and reduced adherence (Breen et al., 2007; van Deventer et al., 2009). Time constraints on clinic staff lead to nurses providing a service of dispensing medication with little psychosocial intervention [11]. Furthermore a lack of orientation and skills of service providers towards holistic and chronic care is also an issue, although DOH is making inroads into addressing this (Mahomed et al., 2014). DOH has in fact made important progress towards the

provision of comprehensive mental health services, particularly through the development of the National Mental Health Policy Framework and Strategic Plan 2013-2020 (DOH, 2013). While this includes provision for community residential care and day care services as well as task-shared community-based rehabilitation programmes (PSR) in all provinces, implementation remains a challenge. There is however growing evidence from LMIC on task-shared interventions for PSR (e.g. (Chatterjee et al., 2014)) and a recent study showed potential for task-shared PSR in low-resource South African settings (Brooke-Sumner C., 2015). The National Mental Health Policy highlights the role of intersectoral collaboration between Departments of Education, Social Development, Labour, Criminal Justice, Human Settlements and NGOs. Some progress is noted to have been made on intersectoral collaboration at the national level but at the provincial and district levels such collaboration is rare (DOH, 2013). A key provision of this policy is the establishment of specialist mental health teams at district level which will have responsibility for operationalisation of the framework and have important potential to move forward progress on intersectoral collaboration at the district level.

This study aims to document perspectives of a range of key informants regarding current challenges and the way forward for intersectoral provision of PSR. This was done with the view of providing recommendations for strengthening intersectoral collaboration. These insights may be of use to other middle income countries

contending with the complexity of intersectoral working, as well as to low income countries, particularly in Africa, which may have different policy and service delivery contexts, but which could benefit from a strengthened intersectoral approach as mental health services develop.

Methods

Study context

This study is a subcomponent of The Programme for Improving Mental Health Care (PRIME), a research consortium implementing interventions for priority mental disorders in low-resource settings (Lund, 2012). PRIME in South Africa conducted a situation analysis which showed limited provision of community-based PSR (Hanlon et al., 2014) in the PRIME study district, Dr Kenneth Kaunda District, North West Province (Petersen I, In Press). PRIME is also implementing a district mental health plan, incorporating a collaborative care PSR component for people with schizophrenia reported elsewhere (Brooke-Sumner, 2014; Brooke-Sumner C., 2015; Petersen I, In Press).

Design

An in-depth qualitative approach was employed to investigate perspectives of key informants. Semi-structured in-depth interviews were used to generate qualitative data reported here based on the Consolidated Criteria for Reporting Qualitative

Research (COREQ) checklist guidance (Tong et al., 2007). The framework method of analysis was used, which is regarded as suitable for distilling recommendations for guiding health systems and policy development (Gale et al., 2013). Advantages of this approach for this study include its suitability for use for individual interview data from different types of participants and the ability to easily compare responses between participants using a framework matrix (Ritchie & Spencer, 1994).

Sample and procedure

Purposive sampling was used to recruit key informants (24 in total) comprising managers and policy makers at national, provincial and district levels. Twenty-four in-depth semi-structured interviews were conducted with 16 key informants from DOH (3 national level representatives (policy makers), 4 provincial level representatives (health programme planners), 9 district level representatives (primary health care managers, nurses, mental health coordinator); 2 key informants from the DOSD (1 national level representative, 1 provincial level representative); 4 key informants from the NGO the South African Federation for Mental Health (1 national level representative, 3 district level representatives) as well as one key informant from a service user organisation at national level. Interviews were conducted in person or telephonically. Interviews were conducted in English by the first author and an MPsych graduate, lasted between 45 minutes and 1 hour, and were recorded and transcribed verbatim, with the participants' consent.

Analysis

NVivo10 data analysis software was used to store data and help conduct framework analysis. The process of framework analysis, conducted by the first author, incorporated familiarisation with the data through review, application of the framework to enable initial coding, identification of subthemes within the framework through inductive coding and refining of codes and themes (Gale et al., 2013; Lacey & Luff, 2001; Ritchie & Spencer, 1994) until no new themes emerged. Major themes of 'Views on current levels of intersectoral collaboration', 'Challenges to intersectoral collaboration' and 'Strategies for addressing challenges' formed the initial coding framework, with additional themes being added as coding of data took place. The data analysis, while employing a framework, did allow for flexibility and emergent themes throughout.

Ethical considerations

Ethical approval for the study was granted by the Biomedical Research Ethics Committee (BREC) at the University of KwaZulu-Natal (approval numbers BE407/13; HSS/0623/012D) and the University of Cape Town (UCT HREC 412/2011). Participants were informed as to the aims and scope of the interviews and as to the voluntary nature of their participation. Informed consent was obtained from all participants.

Anonymity of respondents' data was ensured throughout analysis and writing up through allocation of identifier codes. Interviews were stored on password-protected computers.

Results

1. Theme 1: Views on current levels of intersectoral collaboration

Participants from DOH at district (6) and provincial (3) level, as well as the DOSD provincial representative and NGO (2 district, 1 national) and the service user representatives agreed that existing levels of intersectoral collaboration were inadequate, with two stating that collaboration was 'almost zero' and that there was 'no collaboration' at district level. However, several participants did describe examples of intersectoral collaboration directed by the initiatives of individual staff and relationships built between sectors in an unstructured way. A DOSD provincial representative cited a case in which a person with schizophrenia was identified by the DOSD provincial office for participation in a Department of Public Works employment programme for people with disabilities. The service user organisation representative (based in Gauteng province) described the role of the DOH mental health coordinator who visited their community residential facility in strengthening relationships between DOH and NGOs.

'I think she [DOH mental health coordinator] has monthly meetings with representatives from all the NGOs...and she has developed quite an open communication. She does visit the [community residential] centre now and again and what I like is that she speaks to the residents... to check that they are happy with the service they receive.' – Service user representative 1

2. Theme 2 Current challenges to intersectoral collaboration

Participants identified three main challenges, reported here as subthemes.

2.1 Subtheme 1: Lack of communication and structured working relationship

Participants from all sectors and all levels cited lack of structured relationships and effective communication as a major barrier to intersectoral work. At district level, a DOH representative described challenges in referring and following up mental health service users to DOSD since social workers were based in the district office not in the community and there was no back-referral or established communication mechanism.

'It's a challenge because of the communication channel that we have been told to use to access the social worker. You are told that you have to write a letter and explain your problem and send it over to Social Development. We don't know who is actually receiving it and which channels is it going through. We don't even get feedback if the social worker was there.' - DOH District representative 10

A DOH provincial representative identified the challenge of people within DOH and

other sectors working in 'silos' focusing on their objectives and personal recognition. A district level NGO representative described individualised cases where communication with DOH was functional through specific relationships with clinic staff, but described a major challenge to their work due to lack of information (due to confidentiality concerns) provided to NGOs on diagnosis of patients being down-referred from psychiatric hospitals. The National NGO representative corroborated this and made the link between the lack of communication and lack of service delivery and holistic treatment of clients.

'I think there needs to be a proper structure. At this stage there is no communication.

And lack of communication actually has a detrimental effect of no service delivery.' -

NGO National representative 1

DOH, DOSD and NGO representatives described the lack of a functioning coordination forum to enable communication. One district level DOH representative described a forum that had been set up but which experienced challenges in that representatives would fail to attend the meeting due to conflicting priorities. By contrast, a district level NGO representative described being part of a forum on disability, which did not have a representative from DOH. Two DOH and one DOSD provincial representative noted the lack of communication and working structure at district and lower levels, despite the Social Development 'cluster' (Departments of Health, Social Development, Education, Children and People with Disabilities) being present at provincial level.

'At provincial levels, the departments are arranged into clusters, so there's the Social

Development cluster And I've sat at those levels [district, ward], and the practical integration is just not there at all. If that was to be effective, that same structure [Social Development cluster] needs to be in place at district level, at a sub-district level and at a ward level.' - DOH Provincial representative 1

2.2 Subtheme 2: Problem delineating roles

The majority of participants described ongoing lack of clarity as to the roles of the different sectors in PSR. Respondents had varying opinions as to the role to be played by sectors other than their own and overall the respondents from DOH and NGO sectors felt that DOSD inadequately fulfilled its role. This was exemplified in the provision of community-based residential facilities for people with severe mental illness. A DOH national representative noted that this requires a 'number of inputs' from Housing and Social Development in particular and the inter-dependence of inputs from the different sectors for a comprehensive service was seen to further complicate the relationship between sectors.

'But when it comes to psychosocial rehabilitation, it becomes a bit tricky because, for one to provide psychosocial rehabilitation and community-based residential services, there are a number of inputs...for a district to establish a community residential facility, we would need capital funding for the structure. And currently, Social Development is saying, we are not the ones to provide a structure. We will just provide the rehab services, we'll provide social grants, you know. So it becomes complex for the

Department of Health to implement community based services without the other parties also bringing their input on the table.' - DOH national representative 3

A DOH provincial representative felt that provision and management of community residential services is not recognised as a health 'competency', leading to the ongoing question as to whether DOH or DOSD should manage these facilities. By contrast, a DOH national representative noted that mental health care users access services initially through hospitals and clinics, creating the expectation from DOSD that DOH should bear responsibility for ongoing support.

'If we look at mental health care users, Health is the one that is serving the users. So, the possibility is that... will the Department of Social Development really support what their policies say around provision of residential facilities?.' - DOH national representative 3

Another DOH representative acknowledged that social workers and occupational therapists were key to provision of PSR, and while these cadres are employed by DOH he questioned whether their numbers are sufficient and whether they were accessible to mental health users residing in the community.

From the DOSD perspective, nationally the main challenge seemed to be the lack of a clear strategy that outlines the role to be played by DOSD. A national level DOH representative felt that the main role of DOSD is provision of disability grants, and acknowledged that the partial funding by this department to NGOs providing mental health services may be inadequate. DOSD representatives were clear on their

framework for action, with NGOs funded by DOSD representing their 'implementation arm' in a service delivery model enabling local organisations to respond to needs in their community.

From the NGO perspective, the national representative recognised their role in provision of community services with DOSD funding, but thought that the focus of DOH in providing for needs in a biomedical model (diagnosis and medication) with a lack of focus on psychosocial support, and the corresponding reluctance of DOH to hire social workers (seeing this as mandate of Social Development) led to a failure in continuity of care.

'Health is very good at saying 'we will train foot soldiers, volunteers and home care workers', but they will not employ social workers because that lies with Social Development.' - NGO National representative 1

A NGO district representative also felt that DOSD could have a more active role in providing services (e.g. support groups and awareness campaigns).

Representatives from DOH, DOSD and the NGO national representative all felt that the lack of a service level agreement meant that it was difficult to ensure provision for sector responsibilities. The DOH and DOSD representatives drew the comparison to the substance abuse plan in which sectors' roles are elaborated and clarified in signed agreements. Despite lack of clarity on specific roles, participants from the DOH, DOSD and NGO sectors broadly agreed that 'leadership' on provision of PSR services and

resourcing should come from DOH. One DOH national representative cited the need for health to lead on the reorganisation of services to ensure resources spent on specialist facilities filter to community care.

'So we're going to organise the system, we're going to improve the system, so we take the leadership ... if there are things that are not being done, we have to do them. Health must stimulate that work.' - DOH National representative 2

DOH and DOSD representatives acknowledged that the DOSD model of funding NGOs in communities to provide services was an appropriate strategy for delivery of community-based services.

2.3 Subtheme 3 Perceived lack of support from other sectors

Representatives from all sectors held perceptions of lack of support and trust in other sectors to fulfil their roles. Several DOH representatives described challenges partnering with DOSD. District DOH representatives described challenges in accessing DOSD social workers assigned to their health facilities, acknowledging that social workers seemed overburdened.

'They [social workers] have wards where they work in, but the minute we ask them to go to a certain address then they say, no it's not my area... that makes it quite difficult for us.' - DOH District representative 3

However it was acknowledged by a DOH national representative that there is strong support at national level from DOSD in terms of the overall community development approach within in which PSR is located.

'If you find gaps [in PSR], your remedies are largely around developing a community ... so that's development work which largely Social Development is well-skilled in facilitating. So I know that my colleague [in DOSD] has the interaction at national level to align the policies and they agree on what needs to be done..' - DOH National representative 2

An NGO district representative described the ongoing struggle to access funding from DOSD..

'Interviewer: So the service needs to be set up and running before?

Respondent: Yes, before they will give us any funding. And the thing is that, we have no assurance that if we start rendering the service this month next month we will receive subsidy. There are some organisations that have been rendering services for long years not receiving subsidy and we do not have the funds to do that.' - NGO District representative 1

The service user representative perceived a lack of support from DOSD in their failure to provide for the specific need for psychologists in community residential facilities and to provide collaboration and support necessary in providing the service.

'I think they [DOSD] are too little involved. ...They are not too actively involved in kind of partnering and saying let us look at more effective ways... let us look at a bit of research on psychosocial rehabilitation, what models work best. You know, kind of that collaboration and support. I am not talking only about funding, but other support.' – Service user representative 1

From the DOSD perspective, a Provincial DOSD representative described difficulties

in working with DOH as a partner and particularly a lack of joint working between DOSD disability coordinators and health staff in facilities, and on raising awareness around psychosocial disability (i.e. the impaired social and role functioning caused by mental illnesses).

3. Theme 3: Strategies for addressing challenges

Participants identified three major strategies to address the above challenges, reported here as subthemes.

3.1 Subtheme 1: Promoting clarity on roles

Participants generally agreed on the need for roles of sectors and staff to be clarified. Respondents from DOH district and national levels emphasized that role clarification would enable better care specifically by allowing more efficient referrals between the sectors (e.g. between DOH and NGOs in the community).

'...role verification for each of the departments [is needed], so that they know exactly what is their role, and how they can assist. Say for instance an NGO like Mental Health [Society], they are so knowledgeable, whereas maybe the skills of professional nurses on how to manage a client on community level are maybe limited.' - DOH District representative 4

In terms of the specifics of the roles each sector should be playing, participants described activities that reflect the current activities of the different sectors, with the

suggestion being that performance and fulfilment of roles be strengthened.

3.1.1 Role of DOH

Participants agreed that DOH should take the lead role in improving the integrated care of people with severe mental illness through national to provincial and district coordination of the intersectoral provision of services. Three DOH national representatives described a need for strengthening capacity at provincial level to enable health service planners and managers to effectively conduct integrated planning with other departments.

'... basically our view is that if we can strengthen the capacity for the provincial offices to consult, develop plans together, find the other partners who need to be part of it [PSR]we should be able to stimulate this kind of work and ensure that intersectoral collaboration takes place' - DOH national representative 2

District DOH representatives and the NGO national representative highlighted the need for a strengthened role of DOH staff in providing psychoeducation for service users and families (health education on the mental illness and its management). District level DOH representatives cited a need for an increased role of community health workers in encouraging the involvement of community members and family in ongoing support and referring mental health users to support groups. A specific role of specialist mental health teams laid out in the new Mental Health policy was also articulated by a DOH national representative, in that they should be responsible for creating and maintaining a plan covering gaps in current service provision and

setting up mechanisms for intersectoral collaboration at the district level.

'And in the terms of reference of that district mental health team, this is one of the areas that we listed – that they should be able to produce a plan for a district. For instance, look at where are the gaps in these areas, create a structure ... create mechanisms of collaborating with the other key sectors, whether it's Education, Social Development and all that.' - DOH national representative 2

District and provincial DOH representatives also described the need for community-based DOH-employed social workers (as part of specialist mental health teams) and acknowledged that additional numbers of social workers would need to be employed by DOH.

'I know that in other places they have medical social workers at the hospitals but not at primary health care. We don't have a social worker. Again, in most cases we find that the psychologist will then report to you that most of the cases need social workers intervention and therefore it becomes a challenge with referral and also giving feedback to other departments.' - DOH District representative 2

3.1.2 Role of DOSD

DOH district participants identified key roles of DOSD in the provision of disability grants through SASSA. DOH and DOSD national representatives felt the main role of DOSD going forward was to strengthen the current mode of service provision through funding a wider network of NGOs. Beyond this, DOSD was also identified in having a role in an overall community development approach encouraging 'informal

services' and support in the community through empowering families and community members to better address the needs in their community

'So Social Development, if we are to give effect to the development of community-based mental health services... need to embrace the user organisations, ensure that they work with families and encourage, beyond what government can do, also encourage what we call the development of informal services. Because, look, I think we appreciate that, yes, there's a lot of government should facilitate, or the two departments [Health, Social Development] should do, but some of the good innovations can be found when you encourage communities informally to address their needs. It's a lot of development work.' - DOH national representative 2

While DOH and DOSD participants acknowledged that DOSD social workers were overwhelmed with other social care needs, DOH district representatives also held the perspective that they needed to find a way to work in conjunction with social workers from planned specialist mental health teams. They also highlighted the importance of a functioning referral system between health facilities (including specialist mental health teams) and DOSD social workers.

The DOSD provincial representative felt that DOSD social workers did have more of a role to play in addressing the significant strain on families of mental health service users. This participant also suggested the need for a mental health specialisation for DOSD social workers, similar to the current specialisation in children's services. The NGO national representative suggested that DOSD should be placing a departmental

social worker in all primary health facilities, which was the case in some areas but not standardised across the provinces.

'But that would be a recommendation, that while Health provides at a primary setting a nurse, and access to a psychiatrist, Social Development should be providing a social worker at that level.' - NGO national representative 1

3.1.3 Role of NGOs

Discussion on the role of NGOs centred on the Mental Health Societies (provincial arms of the South African Federation for Mental Health) as these are the main NGOs currently providing services. Representatives from all sectors agreed that NGOs were best placed to provide PSR services on the ground. The NGO national representative agreed with this perspective but highlighted the need for adequate resources to be directed to these services.

'...so it is the state's responsibility to make sure the structures and the resources are in place. It is wonderful if civil society is used because that's where the skills lie, in terms of civil society providing a service which government needs to purchase. But it has to be a valuable service, so not a totally cheap service where you compromise on the service delivery.' - NGO national representative 1

DOH district and national participants suggested a need for a wider network of NGOs providing support services. They also identified key roles of NGOs in managing residential facilities, providing for productive or income generating activities and addressing 'general social needs'. The DOSD national representative held the

perception that NGOs also have a key role to play in empowering mental health service users be involved themselves in service provision.

'...you need to actually make sure that the NGOs are also consulted ... because we look at empowering mental health care users, or people with mental disabilities to get employed or run businesses, or render services. What needs to actually happen is because of the scarcity of resources ... we then can look into capacitating people with disabilities themselves, and the family members who are passionate or understand this kind of illness or disability, to be part of the service delivery at provincial and local level.' - DOSD national representative 1

3.1.4 Need for a coordination role

Participants involved in the direct provision of services strongly emphasized the need for a focal person who would coordinate PSR services and collaboration between sectors. DOH representatives at district level identified the person to fulfil this role as the DOH district mental health coordinator (a function that is only present in some districts and is likely to be replaced by specialist mental health teams, in keeping with the new national Mental Health Policy Framework (2013-2020)). Specific roles for this coordination function included liaising with intersectoral partners (service providers at management level), community members and ward counsellors, taking up PSR issues at social cluster meetings, and contributing to financial and operational planning for PSR services.

3.1.5 Need for a case management role

Participants also identified the need for a focal person who would fulfil the case management role for individual patients. This included follow up of patients in the community, working with families, liaising with hospital staff and other service providers on referrals, and following up treatment defaulters. NGO participants, those involved in current provision of these services, felt this should be a social worker.

'...social workers play the key role of coordination, of making sure there is follow up, making sure the family support structures are in place and other support structures.

So it's the community development part where social workers are involved' – NGO national representative 1

3.2 Subtheme 2 Improving communication and structured working relationship

Participants identified four strategies for improving the communication and working relationship between the sectors.

3.2.1 Leadership

DOH representatives from district, provincial and national levels called for leadership in intersectoral collaboration from DOH. Participants from the different levels of service delivery had differing perspectives on how this should take place. Some district and provincial level participants felt that leadership should come from high

levels of the health system.

'Whatever comes from the political side and is emphasized by politicians has more value because the people listen to politicians. If we can have politicians emphasising the importance of support from the community and also improving services, then to some extent we can improve the services.' - DOH district representative 9

One provincial DOH representative also emphasized the need for leadership at all levels:

'We are envisaging for this kind of collaboration to take place at all levels, whereby even the executive managers meet and talk about particular issues ... so that when the implementers come in, it's not about them having to pave the way forward for how they are going to work.' - DOH provincial representative 4

3.2.2 Formalised relationships

DOSD national and provincial representatives specifically noted the need for a memorandum of understanding to provide a grounding for the working relationship between DOH and DOSD. While only one DOH district representative articulated the need for a service level agreement, other DOH participants noted the lack of structure to the intersectoral relationship.

'I personally believe there should be something like a memorandum of understanding between the departments, in order to enforce a formal relationship in terms of service provision.' - DOSD Provincial representative 1

3.2.3 Improving communication and referrals between sectors

The need for regular intersectoral meetings was expressed by DOH and NGO district representatives. Similarly a DOH provincial representative suggested the need for closer working relationships with DOSD counterparts including daily communication.

'Maybe just getting the system in place where there are regular meetings to say this is what we struggle with...because there are no meetings between health and NGO's and social development focusing only on people with disability.' - NGO District representative 4

Four DOH district representatives identified the existing sub-district Social Development Cluster meetings as a crucial opportunity for intersectoral communication, while one acknowledged that mental health had not been a priority in these meetings and another questioned the effectiveness of the structure. One made the suggestion that ward councillors also be involved in these meetings and another suggested the need to involve traditional healers.

'Each sub-district has a Social [Development] Cluster meeting with the different intersectoral partners, and that's where there should be some integration. It's not very functional, what happens is that ... like Social Development will send one person this week and then next month another person so there's no continuity, so the same issues come out at every meeting and nothing really moves. But that would be where it should happen, but it's not happening.' - DOH District representative 8

Participants from all sectors described the need to improve referrals between the sectors. Specifically the need for an effective referral and feedback pathway between DOH, NGOs and DOSD social workers was highlighted by a DOH district representative and the NGO national representative. Social workers were seen as providing the crucial link from health services to other services and resources in the community.

'Once the person has seen the psychiatrist and is on medication where do you refer to? And that referral must be a proper one, you can't just refer to a social work department or the Department of Social Development...that task team should be in contact with one another all the time.' - NGO national representative 1

In line with this, a DOH national representative highlighted that a key role of the specialist mental health teams outlined in the Mental Health Strategy will be in clarifying referral pathways and ensuring continuity of care.

3.3 Subtheme 3: Appropriate resource allocation for PSR

Contrasting views between national and district level participants on allocation of resources for PSR emerged. DOH and NGO representatives at district level felt strongly that additional resources should be allocated to their organisations or to community mental health services.

'For example we have an HIV budget and HIV funds that are continually announced at budget speeches ...f this service for mental health [PSR] can be integrated it will be a great improvement to our services because then it means you don't have to struggle

to get resources.' - DOH district representative 9.

However DOH national representatives and the NGO national representative felt that resources for PSR were available taking into consideration resources between the sectors, although currently not specifically allocated to PSR. One DOH national representative felt that the likelihood of getting more resources for mental health is low at this point so what is needed is an analysis of services provided and reorganisation of budgets to enable more efficient use of resources. Another highlighted the need for PSR services to be defined in district mental health budgets for community-based services, indicating that the budgeting process in this regard needs improvement across provinces.

'Because service delivery is within Social Development, within a specific subdirectorate, and then also within Health, it is very isolated. And these are at national structures, but when it goes down to the provincial I don't think that... in terms of allocation of funding... it's not stipulated that within mental health this is the service package. I think that the biggest issue is the lack of interdepartmental cooperation, so there is budget allocated to different departments and if this is utilized correctly then these resources are there to be used.' - NGO National representative 1.

3.3.1 Provision of infrastructure

DOH representatives from district, provincial and national as well as the service user representative emphasized that a priority for future intersectoral work should be the provision of infrastructure. This was seen to be both through creation of new

community residential facilities and through harnessing practical strategies to provide space for psychosocial support services (e.g. converted cargo containers used for support groups – a strategy used for provision of variety of services in overcrowded clinics in South Africa).

'You know I think government should be more involved...you know supporting NGOs more financially and to establish more such [community residential] centres because even with the fees involved here there is always a waiting list. There is not enough space to accommodate everybody.' - Service user representative 1.

Discussion

This study was undertaken against a backdrop of low levels of service provision for community-based PSR in South Africa, particularly in rural areas (Petersen & Lund, 2011), and limited intersectoral collaboration (Marais & Petersen, 2015; Skeen et al., 2010). Although local contexts and policy and resourcing environments differ, similar challenges are likely being faced in other African countries and wider LMIC contexts. South Africa is however poised to benefit from positive recent developments such as the introduction of new National Mental Health Policy and plans for roll out of specialist district mental health teams (DOH, 2013). The study aimed to investigate challenges to intersectoral working between governmental and non-governmental actors for the provision of community-based PSR services and to gain perspectives from key informants on strategies for addressing challenges. Strategies identified are

particularly relevant for other middle income countries with similar resourcing environments and service delivery platforms, but also for lower income countries seeking to make progress on provision of comprehensive mental health services.

The majority of participants in this study agreed that current levels of intersectoral collaboration for PSR were low, suggesting lack of progress since previous South African research describing intersectoral working at national level but not at district levels (Skeen et al., 2010). Participants identified isolated cases of intersectoral working, which were not supported by organisational structures. This type of working strategy has been identified internationally by WHO reports on intersectoral action for health which recognize that 'small scale, local action' gives motivated individuals opportunities to form strong, productive relationships. However dependence on individual action is not sustainable for long-term provision of country-wide services (WHO, 1997). WHO case studies on intersectoral action for health suggest the need for involvement of a variety of intersectoral partners, each with support from their own organisation for involvement in the intersectoral action (WHO, 2008). For example the Sonagachi HIV/AIDS International Project (SHIP) in India was based on a partnership between WHO, All India Institute of Hygiene and Public Health (AIIPH), the British Council, and a number of Ministries and local NGOs. This project was aimed at sex workers in Kolkata, initially aiming to provide treatment and prevention of sexually transmitted infections in sex workers in the area.

The involvement of partners whose work focused on outcomes beyond direct health outcomes led to broader economic empowerment of sex workers as a result of literacy and microcredit programmes and the institution of a member organisation (WHO, 2008)

Key challenges to intersectoral work that emerged from the data were (i) inadequate communication and structure in working relationships; (ii) the ongoing challenge of delineating roles and responsibilities; and (iii) a perceived lack of support between sectors. Although there is strong recognition in the public health sphere internationally of the need for intersectoral collaboration, even for HIC there is little peer reviewed evidence on the real-world application of this strategy (Chircop, 2015). Challenges identified in this study however do mirror those identified in a HIC context in which a lack of culture of 'working together', lack of knowledge of one sector on the work of other sectors, and lack of structures and guidelines for joint work have also been identified as particular challenges (Darlington & Feeney, 2008).

Key informants provided several feasible strategies for addressing these challenges, outlined below. These strategies correspond well with research from HIC indicating success factors for intersectoral working to be effective communication and planning at both the organisational and service-delivery levels; improving relevant professionals' knowledge and skills; and appropriate resource allocation (Chircop,

2015; Darlington & Feeney, 2008; WHO, 2008). This suggests the relevance of the recommendations from this study both to South African policy makers and health programmers, but also to those in other African countries and beyond.

Strategies identified by participants for improving intersectoral collaboration for PSR

1. Promoting sector fulfilment of roles

Participants in this study identified the need to clarify, in a practical sense, the roles of intersectoral partners in PSR programming, to ensure understanding between sectors of other sectors' roles, and to build capacity where needed to fulfil these roles. To some extent different participants had different solutions to problems identified (e.g. increasing funding to NGOs *vs* direct employment by DOH or DOSD of more social workers). While this underscores the need for sector role clarification, it also suggests potential for actors to move beyond their previously defined roles through sharing resources and responsibilities in the intersectoral partnership.

Proposed DOH role

Given the recognized role (supported by most participants in this study) of DOH in leading the process of provision of PSR services, recommendations for DOH action at the service delivery level and at the organizational/planning level were made.

At the service delivery level the role of tertiary staff in diagnosis and of primary health workers in ongoing medication management was well supported by participants in this study. Recommendations for PHC nurses include improving their capacity to 'create an informed, motivated, and adherent patient' (Mahomed et al., 2014) in line with the development of the South African Health System which is embracing an Integrated Chronic Disease Management Model (ICDM) (Mahomed et al., 2014). PHC nurse provision of psychoeducation for those with severe mental disorders and their caregivers is the most obvious activity indicated. There is evidence that even hospital based staff in South Africa see themselves as ill equipped to provide PSR, given the lack of focus of previous mental health policies and training on this area [34] so significant inputs for capacity building would be required. The acknowledgement of participants in this study of the need for DOH service providers to provide a lead role in provision of PSR also points to the role of the PHC nurse in 'case management', the need for which was emphasized. In this context the case management role would of necessity be scaled back in comparison to the HIC Intensive Case Management model (Dieterich et al., 2010b) but would entail maintaining contact with patients, tracking adherence and hospital/specialist referrals, and making referrals to other services (e.g. social services) as required, and is in line with the ICDM call for an increased role in holistic care for PHC nurses (Mahomed et al., 2014). Other developments in line with the ICDM would be additional 'case management' functions (e.g. working with

families, health promotion, initiation of support groups) to be provided by ward-based outreach teams (Mahomed et al., 2014), and promotion of medication adherence and tracing of treatment defaulters for all chronic conditions by current HIV counsellors (Mahomed et al., 2014). The role of primary health care workers at clinic level in providing the case management function and managing referrals at service points may be applicable to a variety of LMIC. In very low resource contexts this function may feasibly be provided by another cadre (e.g. community health workers).

At the planning/management level, the South African National Mental Health Policy Framework and Strategic plan has the objective of roll-out of at least one specialist mental health team per district by the end of 2015 (DOH, 2013) which provides a clear opportunity for progress on intersectoral working. The Terms of Reference for these specialist teams cover their role in improving referral pathways from primary care to specialist services, but do not emphasise referral to other services in other sectors (DOH, 2013). This could be a key opportunity for improvement of intersectoral working at the district level. These teams would also need to include specifics for intersectoral collaboration in the development of district mental health care plans as a core objective under their terms of reference (DOH, 2013). The role of referral of people with severe mental illness to primary health services, and to the social/community services that are available, is one that could be strengthened in the work of, for example, community health workers, who, as indicated, may be present even in very low resource settings in LMIC contexts.

Proposed DOSD role

Similar to the role of DOH in provision for biomedical aspects of treatment, the role of DOSD in provision of social grants and funding NGOs was well supported by participants in this study. Some participants in this study recommended that DOSD should take a broader approach. Since PSR is grounded in a community-based rehabilitation framework, services should not focus only on psychosocial support but also on social inclusion and equalisation of opportunities for people with psychosocial disability (Chappell & Johannsmeier, 2009; I., 2010). This aligns with growing acknowledgement across LMIC of the need to dovetail approaches for mental health and social development (I., 2010), although there has been limited integration of mental health into social development in some countries' development models to date (Plagerson, 2015). DOSD can have a key role in incorporating service users with mental illness into their overall community development approach, specifically to address calls to alleviate the impact of poverty on those with severe mental illness (Lund et al., 2011; Patel et al.). Increasing evidence is mounting (largely from NGOs such as BasicNeeds) on the feasibility, cost effectiveness and benefit of inclusion of those with mental disorders in community development models (de Menil et al., 2015). This approach would also support South African progress on alignment with UN proposed sustainable development goals which include a target to promote mental health and wellbeing (Buse & Hawkes, 2015). Practically, integration across the mental health and social development sectors would be beneficial across LMICs

and will be encouraged by development of cross cutting indicators for monitoring progress (e.g. mental health outcomes of social development programmes) (Plagerson, 2015).

The unavailability, described by participants in this study, of social workers to meet the needs of mental health service users underscores previous calls for national training centres for psychiatric social workers in South Africa (Bhana et al., 2010b). General Social Workers are overburdened and focused on the needs of orphans and vulnerable children and families living in poverty – similar challenges are likely being faced particularly in African countries and those with high rates of HIV prevalence similar to South Africa. More Social workers focused on psychosocial disability are greatly needed, but there are unlikely to be sufficient numbers in the near future, underscoring the need for para professionals and working in a task-sharing model. The suggestion was also made in this study to assign DOSD social workers to primary health clinics to work closely with the district mental health team. However this approach could be hampered since levels of stigma against people with severe mental illnesses, particularly schizophrenia, are high in South Africa (Sorsdahl & Stein, 2010). Social workers without previous experience of working with mental health care users may need training and support to reduce stigmatising behaviour.

DOSD participants in this study had somewhat limited knowledge of the South African Mental Health Care Act and the National Mental Health Policy, and of

psychosocial disability in general, which may have contributed to the perspective that addressing this is a 'health' issue. This is likely a challenge in other relevant sectors (e.g. housing) (Skeen et al., 2010) . Mutual training between sectors may be beneficial for intersectoral working (Chircop, 2015) in South Africa and other LMIC contexts particularly to work towards reduction of stigma against mental health care users.

2. Improving communication, structured working relationships and leadership

Communication challenges were identified between the majority of participants in the study, both at the level of individuals mental health providers (e.g. between health workers and social workers) and between different levels (provincial, district) of the health and social service systems. Clarifying and supporting pathways for communication and referral between levels of the health system is a recognised priority for the planned district mental health teams in South Africa (DOH, 2013) but work on pathways with DOSD and other community services needs to be similarly emphasized. Several participants also identified the existing Social Development Clusters as the key avenue for potential communication on issues relating to PSR services. A vital part of the district mental health team planning/management role as identified earlier could be in the representation of issues relating to PSR in this forum as well as a promoting the institution of cluster meetings if these do not exist. Supporting this in the South African context is the documented need across the sectors for increasing capacity at provincial level for managers to conduct operational

planning in an integrated way (Marais & Petersen, 2015). Other LMICs may have similar fora in place and it is possible that similar challenges hinder their functionality. Where possible these fora should be harnessed and strengthened for the promotion of PSR. In settings where they do not exist, their set up would represent a key step towards promoting intersectoral working for PSR and other health and social development issues. A directive from national and provincial levels of the Social Development Cluster (or its equivalent in other LMIC) for requirements for well-functioning clusters with regular meetings and monitored actions would increase accountability for intersectoral work.

This study highlighted that at the provincial and district level, service level agreements between intersectoral partners are not present, but would be beneficial. A key challenge for many countries is the focus on limited mandates for government departments and the fact that each department has its own specific 'language and culture' – which leads to people working in 'silos' and competing for resources (WHO, 1997), which was mentioned by several participants in this study. A written agreement with roles and responsibilities for service providers to assemble a comprehensive PSR service at district level, with negotiated and agreed input from all sectors, is a feasible approach to address this challenge in South Africa and elsewhere. Key performance indicators on intersectoral action for service providers and managers in the sectors may also be relevant.

In terms of leadership, the main area of need seems to be clear directives from DOH for different sectors concerning implementation of PSR services from the national to provincial level (Draper, 2009) and beyond this to district level. Leadership for intersectoral collaboration by Health sectors across LMIC at national and provincial levels will require building trust and enabling other sectors to focus on the broader benefits to society of intersectoral action (e.g. social justice and equity) (WHO, 1997) as well as showing clearly why intersectoral action is appropriate for provision of this service (WHO, 2008). These in turn should help to make mental health relevant to other sectors and enable pooled resources to flow in the required direction. Governments as a whole also need to foster a more positive orientation to intersectoral action as part of their 'fundamental stewardship responsibility in health' (WHO, 1997) (Vega & Irwin, 2004). This means a recognition from high levels of leadership that this way of working needs to be built in to structures and working practices, and therefore requires a dedicated budget (e.g. for monitoring frameworks for intersectoral action) (WHO, 1997).

3. Direction of available resources to community-based PSR services

Budget constraints for mental health services are an ongoing challenge, particularly considering the burden of other chronic and communicable diseases in South Africa (Bhana et al., 2010a). This is borne out by the lack of a specific budget for mental health

at district level and at the subdistrict level where services are provided. There is consequently a lack of a budget line specifically for PSR, as highlighted by several participants in this study. With respect to budgets for mental health, the constraints experienced in South Africa (and other LMIC) are unlikely to change in the near future as identified by a DOH national representative in this study. Participants in this study did however highlight the contrast between the lack of provision of PSR services with the substantially more developed substance abuse rehabilitation programme, which has a dedicated funding stream from DOSD, and in which a functional partnership between DOH and DOSD has been instituted. Experience from a variety of countries shows that the wider resource constraints in the public sector, as well as administrative structures, act as an impediment to intersectoral collaboration (Vega & Irwin, 2004) and that long-term sustainable intersectoral action can be costly and time intensive (WHO, 1997). The most discussed need for resource allocation by participants in the study was for the provision of infrastructure and management of community residential facilities which is addressed in the National Mental Health Policy. There were however contrasting perspectives on the availability of resources for PSR services between district and national level participants. District level NGO and DOH representatives felt the effects of scarce resources on the ground and a sense of competition within DOH for different disease priorities affecting the country. This is the manifestation of the public sector resource-constrained environment which fosters competition instead of collaboration between sectors (Jenkins et al., 2011) in many LMIC. By contrast, national representatives generally felt resources for PSR

were available. This reflects knowledge that resources at tertiary level are available, but there remains limited redirection of these resources to community level. There is a crucial need for accountability and assessment of the adequate transfer of resources in this direction (Sunkel, 2014) but reallocation of resources to community services is a complex undertaking for South Africa and other LMIC. There are key learnings from recent progress in Brazil involving negotiation with municipalities for resource reallocation from hospital beds to community mental health services (through Centers of Psychosocial Care – CAPS), residential services, cash transfers and psychosocial support for community integration as well as programmes for employment/income generation for people with mental disorders (Government, 2013). Sixty-six percent of the Brazilian population was estimated to be covered adequately through CAPS services as of 2010. These positive developments have been grounded on ‘political will, adequate financial resources and attention to technical aspects of the implementation’ (Patel, 2015). South Africa and other LMIC will need to bolster each of these to see progress on intersectoral provision of community mental health services. Working with municipalities as a key intersectoral partner was not identified as theme in this study, although one district level DOH participant did highlight the role municipalities could have in provision of community residential facilities. The National Mental Health Policy does state the role of local government in providing for transport, housing and recreational needs of people with mental disabilities (DOH, 2013) but the practical involvement of municipalities as a key partner for intersectoral provision of PSR in South Africa will be an important area for future investigation..

Limitations

A limitation of this study was the focus on perspectives from DOH informants with fewer participants being from DOSD, NGOs and service user organisations. Related to this, lack of perspectives from other intersectoral partners (e.g. housing, labour sectors) may have introduced a bias in perspectives and an incomplete understanding of the way forward for intersectoral collaboration on this issue. Some representatives had previous working relationships with the research group which may have led to a desirability response. The interview schedule also did not ask specifically for success stories so it may not have specifically captured positive perceptions related to intersectoral collaboration.

Future research

As a potential strategy for effective provision of PSR services, observational studies showing how intersectoral work can be implemented in practice (Chircop, 2015) will be valuable. These will allow documentation of good practices and guidelines for intersectoral working. An example in the South African context could be the national substance abuse programme as identified by participants in the study. Observational and evaluative studies of intersectoral working practices would also allow for creation of platforms for knowledge sharing from HIC where intersectoral work may be more well-developed to LMIC, and between LMIC where similar challenges may be faced.

Conclusion

The continuing lack of focus on PSR points to ongoing marginalization of people with severe mental illness and blockage of progress in provision of required services, as has been the case in various African countries (Hanlon et al., 2010). Intersectoral provision of PSR services in South Africa has emerged in this study as a complex challenge due to resource allocation and scarcity, inadequate organizational structures, and lack of trust, communication and clarity on roles. These challenges are clearly substantial, and help to explain lack of progress in the area despite widespread acknowledgement of the importance of working in this way. This study has outlined several directions for progress to address these challenges. How these are addressed will hinge on far-sighted political will and leadership to provide for services for this group of service users, particularly since intersectoral work may only show results in the long term (WHO, 1997). On the other hand, greater cohesion between the health and social development spheres may help to provide the momentum and resources needed for appropriately scaling up services for mental health care users (Plagerson, 2015).

Author contributions

CBS conceptualised the study, contributed to design of interview schedules, conducted some interviews, conducted qualitative analysis, drafted and revised manuscript. CL advised on analysis, reviewed and edited manuscript. IP aided in conceptualisation of the study, contributed to design of interview schedules,

contributed to analysis, reviewed and edited manuscript. The authors declare that they have no competing interests.

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Chapter 7 Discussion and Conclusion

Contributions of the study to PSR in South Africa and LMIC

This PhD study has generated new knowledge and experience on the development and implementation of task-shared PSR for schizophrenia in a low-resource setting. This includes the publication of the first systematic literature review covering acceptability and feasibility of psychosocial interventions for schizophrenia in LMIC. Secondly the study has documented experiences and perceptions of this illness amongst service users and their caregivers in a South African context. This formative research, in conjunction with a participatory intervention development approach with stakeholders relevant to provision of PSR, contributed to the creation of a collaborative care model for schizophrenia for the study district (Petersen et al., 2015). The PhD study has then provided intervention materials, reporting of implementation, and the first preliminary evidence of acceptability, feasibility and benefit of the task-shared approach for PSR in South Africa. It documents collaborative work with a local NGO for implementation as recommended in WHO and South African rehabilitation policies (DOH, 2000; WHO, 2004) and the South African National Mental Health Policy Framework and Strategic Plan (DOH, 2013). The study therefore adds to the nascent body of evidence on task-shared psychosocial interventions in South Africa, (e.g., (Peltzer et al., 2012; Petersen et al., 2014; Rotheram-Borus et al., 2014). The need for this evidence has been recognized for some time (Petersen & Lund, 2011; Petersen et al., 2012) and task-shared community-based PSR is earmarked for implementation in all provinces in the National Mental Health Policy and Strategic Plan (DOH, 2013). The PhD study also adds to the evidence from LMIC for community-based PSR for schizophrenia which while growing [e.g., (Chatterjee et al., 2011; Chatterjee et al., 2014; Chatterjee et al., 2003; Chatterjee et al., 2009)], is acknowledged to include a limited number of well-designed comprehensive intervention studies (Iemmi et al., 2015). Finally the PhD study has contextualised the challenges to wider PSR service delivery

in South Africa in terms of lack of intersectoral collaboration for provision of this service, and has provided recommendations to address this challenge.

Contribution to literature on use of MRC framework for complex interventions in LMIC

The systematic development and piloting of the PSR intervention in this PhD study was undertaken in line with MRC guidance for complex interventions (Craig et al., 2008) and experience of implementing psychosocial interventions for mental health in LMIC contexts since the early 2000s [e.g., (Verdeli et al., 2003)]. Contributions of the study can be framed as contributions to evidence for Step 1 (Development) and Step 2 (Feasibility and piloting) of the MRC Framework, in a low-resource South African context.

MRC Framework Step 1: Contributions to literature on formative research for psychosocial intervention development for schizophrenia

Lack of acceptability of interventions in a specific cultural context is recognized as an implementation barrier (particularly for approaches originally conceptualised in HIC contexts). This has led to the acknowledgement of the need for specific adaptation of interventions through formative work to improve acceptability (Patel et al., 2011). Papers incorporated in this PhD study add to the literature in this field in several respects. Through a systematic review process, Paper 1 contributed practical strategies for improving the acceptability and feasibility of psychosocial interventions for schizophrenia, which may also be relevant in wider low-resource contexts. As detailed in the paper these include involvement of caregivers, addressing experiences of stigma and discrimination, using simplified and appropriate materials, and

incorporating effective systems for maintaining contact with participants. The review also pointed to important current limitations in the field, including the lack of operationalising and reporting on acceptability and feasibility (most especially feasibility factors and costings), a lack of focus on rural areas, and the tendency for interventions to be specialist-delivered and not community-based, as has been suggested by other authors (Chatterjee et al., 2014). This may suggest some resistance among those working in the field to community-based task-sharing approaches for schizophrenia (Patel, 2015). The relatively small amount of feasibility and acceptability data reported in Paper 1 provide impetus for future well-developed LMIC studies on task-shared psychosocial interventions for schizophrenia to appropriately develop the field. A complementary systematic review to that conducted for this PhD, covering effectiveness of the respective psychosocial interventions, was planned to be carried out by another PRIME PhD researcher working with myself. However this was not completed due to time constraints. This will be an important gap in the literature to be filled in the future.

Paper 2 outlined specific contextual factors relevant to the study district by investigating the experiences and perceptions of illness of service users with schizophrenia and their caregivers. Understanding contextual factors and participants' perceptions is increasingly forming a substantial part of intervention research (Balaji et al., 2012a; Chatterjee et al., 2014; Silove & Ward, 2014). The key output of this paper was recommendations (Table 2 in Paper 2) for components for inclusion in the intervention based on needs identified (and tailored for service users and caregivers separately). The most prominent finding was the low levels of knowledge on biomedical aspects of the illness (symptoms, treatment) held by service users and caregivers – suggesting that a significant portion of the intervention be dedicated to psychoeducation. This aligns with literature review showing growing evidence for psychoeducation approaches for patients and caregivers in LMIC [e.g., (Agara & Onibi, 2007; Chan et al., 2009; Kulhara et al.,

2009; Paranthaman et al., 2010)]. The challenges of living in poverty (despite receiving disability grants, which were often seen as inadequate) and the importance of work or income generation for recovery also emerged clearly. These are similar to findings from Indian investigations of desired outcomes for psychosocial interventions for schizophrenia (Balaji et al., 2012a; Balaji et al., 2012b). Other inclusions (see Table 2 Paper 2) were based on evidence of family conflict (notably around managing finances and disability grants) and stigma and discrimination, indicating a need for inclusion of skills for communication, promoting emotional wellbeing and for dealing with experiences of stigma and discrimination. Orientation of non-specialists to the value placed by service users and caregivers on traditional explanatory models of illness and on Christian religion were also identified as central to acceptability indicating areas for specific cultural adaptations of the intervention. Inclusion of the data from the formative work was achieved through developing intervention materials and training to promote acceptability, for example by fostering in intervention workers an understanding of the need to show acceptance of traditional explanatory models, while at the same time providing clear information on biomedical aspects of the illness and treatment. These recommendations for intervention components align to a large extent with the extensive intervention development work that has been conducted for lay-person delivered community care for schizophrenia in India (Chatterjee et al., 2014; Chatterjee et al., 2003; Chatterjee et al., 2009). As the first study of this kind in a low-resource South African context, this PhD study has therefore suggested comparability in factors influencing acceptability across LMIC contexts.

There is a relatively large body of evidence for culturally adapted psychological interventions for depression in LMIC. This includes the MANAS trial in India and THP trial in Pakistan (Patel et al., 2011; Patel et al., 2010; Rahman, 2007), as well as the current PREMIUM

programme for depression and alcohol use disorders in India (Patel et al., 2014) and the ongoing trial for maternal depression in South Africa (AFFIRM) (Lund et al., 2015; Lund et al., 2014). There are also ongoing South African PRIME and COBALT (CO-morBidity of AIDS/ HIV Affective disorder, and Long-Term Health) trials for comorbid depression in chronic care patients on hypertensive and anti-retroviral treatment respectively. These studies show some important areas of overlap with adaptations used in this study (e.g., simplifying language and materials, recognising importance of stress/life problems, use of religious idioms, involving family members) again indicating comparability in acceptability factors across disorders and LMIC contexts. The evidence for cultural adaptation of psychosocial interventions for schizophrenia in LMIC is more limited. However, recent studies of adaptation of cognitive behavioural therapy for schizophrenia (with in-patient populations) in Pakistan have also emphasized consideration of explanatory models of illness that attribute spiritual causes to symptoms, as well as cultural specificities and norms in communication such as assertiveness norms (Habib et al., 2015; Naeem et al., 2015).

Overall, the data from Paper 1 and 2 have served two purposes. Firstly they have added to the evidence on cross-cultural adaptation of psychosocial interventions for schizophrenia in LMIC contexts. Secondly they have provided guidelines for incorporating into the PRIME South Africa PSR intervention to improve its acceptability and appropriateness.

Contribution to experience of developing a collaborative care model for schizophrenia in the South African context

In addition to the formative work described above, other areas of work leading to the development of the intervention, not described fully in the resulting literature, were also undertaken, and contributed significantly to the work of the PhD. Firstly, conceptual modelling (Campbell et al., 2000; Craig et al., 2008) to describe how the intervention was likely to fit with the current provision of care for people with schizophrenia in the district was undertaken through participatory Theory of Change (TOC) workshops. TOC workshops involved mental health service providers in the study district and were part of the wider PRIME process of development of a comprehensive mental health care plan for the district (Petersen et al., 2015). Theory of Change as a tool for programme planning is useful as it separates short, medium and long term outcomes needed to achieve an overall outcome and maps out a causal pathway of the activities needed to achieve the outcome (Breuer et al., 2015). The other main advantage of the TOC approach as used in PRIME has been that it enabled the creation of contextually appropriate mental health care plans and brought relevant stakeholders into the process from the early stages, promoting buy-in and ownership (Breuer et al., 2015). Two TOC workshops were conducted with stakeholders involved in the long-term care of people with schizophrenia. The workshop process involved discussion around the desired outcomes of the schizophrenia component of the mental health care plan for the district, and gaining different perspectives on what the required building blocks to achieve those outcomes would be. With support from other PRIME workers I led the schizophrenia section of the initial TOC workshop (March 2012) with health facility, district, provincial and national level representatives. Follow-up workshops were then conducted to present to stakeholders the suggested mental health plan, including the collaborative care model for schizophrenia which incorporated the PSR

intervention. These TOC processes have been described in several papers (Breuer et al., 2015; Breuer et al., 2014; Petersen et al., 2015).

Secondly, a process of consultation over a period of six months was conducted with two clinicians and researchers currently working in the PSR field in a different South African province (one psychiatric nurse, one psychiatrist). This was specifically around the materials for the intervention, in line with MRC guidance calling for expert consultation (Campbell et al., 2007). Their expert contextual opinion contributed to the triangulation process for the intervention development incorporating (i) formative data on experiences, perceptions and need; (ii) literature review; and (iii) expert opinion (Patel et al., 2011). Each of these were valuable in shaping the development of the intervention and particularly in refining the intervention materials. Both the Facilitator Training Manual and Facilitator Guide had several iterations and were simplified and modified according to expert opinion and Facilitator feedback, in line with experience from development of other mental health interventions (Murray et al., 2013; Patel et al., 2011).

Thirdly, from the outset a key challenge for the intervention was identifying available human resources in the district to facilitate the intervention. CBR approaches are acknowledged to be time and resource intensive (Chatterjee et al., 2003). A core principle of the PRIME research consortium is sustainability and bringing in a new set of intervention workers purely for the purposes of the research study would be in opposition to this principle. In view of this, two potential sources for the relevant human resources were identified. Firstly, DOSD has trained auxiliary social workers (ASWs) in the NW province. Together with a senior member of the PRIME team I conducted an extensive engagement (over a period of more than 18 months)

with DOSD at national level to enable allocation of DOSD ASWs and social worker supervisors to work on the PSR intervention. While 10 DOSD workers were assigned to this task and attended the training for the intervention, when it came to implementation, they were not cleared to participate. While we seemed to have the necessary support at national level for the intervention, the allocation of this cadre of workers to the intervention was dependant on provincial representatives' support and clearance of the ASWs participation, which we were not able to gain. The failure to mobilise resources from this sector is indicative of the difficulties of working in highly resource-constrained contexts and of the socio-political influences that may hamper the required allocation of resources. This was recognized from the outset as a crucial impediment to scalable PSR in South Africa and was investigated in Paper 4. The second potential source for ASW Facilitators was the North West Mental Health Society (NGO). PRIME colleagues and I conducted a similar process of engagement with the South African Federation for Mental Health at national level and then with their provincial arm (the North West Mental Health Society). Through this we were able to secure participation of two ASWs and one social worker for the intervention implementation. This was despite the Mental Health Society being under continuing severe resource constraints (e.g., for provision of transport for ASWs). These two ASWs became the bedrock of the implementation of the PSR intervention and carried out the work in addition to their usual roles. Some of the implications of this are discussed in Paper 3.

MRC Framework Step 2: Feasibility and piloting: Contribution to literature on acceptability and feasibility of task-shared PSR

The MRC guidance outlines the need for understanding the process of implementing the intervention, particularly Facilitators and barriers to acceptability and feasibility that should be addressed before further testing (i.e., additional piloting and definitive outcome evaluation)

(Craig et al., 2008). Investment in this step of intervention testing is crucial for two reasons. Firstly, to enable an understanding of success factors necessary for successful implementation of the intervention which would be a prerequisite for its effectiveness (this is also particularly important to promote scalability of the intervention). The second need is to ensure that future substantial resource investments in more rigorous testing of the intervention (e.g., a randomised controlled trial) are warranted and directed appropriately.

Acceptability

Experience from landmark RCTs from Africa and Asia for task-shared interventions for depression/anxiety indicates key enablers of acceptability include selection of intervention workers from the local community, and effective participatory training (Patel et al., 2011). Acceptability data from this pilot study indicate that these conditions were met (Paper 3). This is supported by (i) high levels of participation in the programme over time; and (ii) participants' positive perceptions of Facilitators. Positive perceptions of Facilitators were linked to their being part of the local community, having previous experience of working with clients with severe mental illness, personal characteristics, and knowledge of the programme. The positive outcomes that emerged prominently from the qualitative formative evaluation data (Paper 3, e.g., improvements in self-esteem, self-care, contribution to households and reduced social isolation) give further support for acceptability of the intervention. These also align with the recovery framework in Indian studies suggesting that important aspects of recovery relate to functional recovery (versus clinical recovery) and improvements in disability (Balaji et al., 2012a; Chatterjee et al., 2014). They also echo the findings of qualitative research with self-help groups for mental health service users in Ghana which showed benefits of these groups to include, amongst other things, improved social inclusion and social support of members (Cohen et al., 2012). In addition to this evidence of acceptability, the fact that apart from some minor changes to the Facilitator Guide (described in Paper 3), the format of the Facilitator

Guide and the content of the intervention were generally acceptable to service users and Facilitators suggests that the intervention is acceptable and warrants further testing. This finding is particularly timely given that the recent Cochrane review of CBR approaches for people with disabilities in LMIC highlighted the need for rigorously developed and tested approaches for CBR for schizophrenia, particularly in sub-Saharan Africa, to enable meta-analysis and understanding of the effectiveness of this approach (Iemmi et al., 2015).

Adjustments to the intervention to improve acceptability

1. Focus on income generating activity

There are however limitations to the positive evidence for acceptability of the intervention. Firstly, the most important barrier to acceptability that emerged in the study was the lack of an effective income generating activity. It is well recognized that poverty and disability compound each other and greatly limit capabilities of people with disabilities (Graham et al., 2012; Mitra, 2006). The hardships described by service users in this study (Paper 1 and Paper 3) caused by living in poverty resonate with those documented in other parts of South Africa (Swartz et al., 2006). Despite the availability of disability grants, participation in work has previously been shown to be an important means of recovery for those with psychiatric disability in South Africa (van Niekerk, 2009). As detailed in Paper 3, the session on Income Generating Activities was designed to initiate discussion and action around a member-directed income generating activity. For example, using a portion of grant funding as “seed funding” for a small business has been reported in other South Africa contexts (Duncan, 2009). No income generating activity was initiated by the end of the three month programme suggesting the need for more structured, longer term support than was possible in this study. Linking with community development projects in line with the experience of the Basic Needs model (Raja et al., 2012) is also indicated. While this was considered in the intervention development, implementation of the intervention was undertaken with the limited resources available (i.e., two ASWs with

two hours a week). Within this context they were unable to provide the level of support needed to introduce an income generating activity and this indicates the need for greater resource investment in the intervention for allocation of ASWs time. For example, the COmmunity care for People with Schizophrenia in India (COPSI) intervention in India comprised an initial intensive engagement phase of three months followed by nine more months of participants' contact with intervention workers (Chatterjee et al., 2014).

Employment or productive activity is a crucial aspect of social inclusion as viewed through the lens of the biopsychosocial model of disability on which the work in this PhD has been premised. Strengthening this aspect of the intervention would be vital to ensure the approach to reducing disability is holistic. This aspect of acceptability is also further illuminated by returning to the capabilities approach, which would suggest that although service users in this study had an income (from the disability grant) they had a significant capability deprivation in being unable to convert this income into a good standard of living (Hopper, 2007; Sen, 1999). Reasons for this include the fact that most service users were supporting other family members in their household (e.g., partner, children, grandchildren) and that they all had low levels of education and limited opportunities for employment or income generation. This aligns with studies in other parts of the country indicating that people with disabilities in South Africa have disproportionately low levels of education (only 20% had finished school in one study) (Graham et al., 2012) as compared with 43.9% of the general population (StatsSA, 2013). So while disability grants are an important part of social welfare support for people with disabilities, for a household where a disability grant is the only source of income it is unlikely that any needs other than the most basic will be met (Graham et al., 2012) leaving little chance for allocating income to enhancing capabilities (e.g., by investing, skills building). Thus the real effect of living in poverty with psychosocial disability for these service users is more severe than what would be imagined looking at income alone. An assessment of service users'

capabilities (as well as functioning) (Burchardt, 2004) could enable the intervention to address not only functioning (e.g., social interactions) but also the capabilities deprivation caused by living in households facing poverty. There is also evidence of poor uptake of disability grants in South Africa due to lack of required documentation, difficulties accessing DOSD offices and lack of understanding of the requirements for grant eligibility (Graham et al., 2012). Serious, high (42%) levels of exclusion of those eligible for disability grants has also been reported (Mitra, 2010). Personal communications with Facilitators from this study indicate that this is a challenge for people with severe mental illness in the Dr Kenneth Kaunda district. In the sample of this study, one eligible service user was not accessing a grant until accompanied by a Facilitator to complete the documentation and assessment (see Paper 3). Facilitators explained that an important part of their role as ASWs at the Mental Health Society was in assisting service users with the administrative aspects of accessing disability grants, which they were unable to do alone. These factors suggest a need to avoid seeing disability grants as a magic bullet and shift focus to enhancing the real capabilities of service users. Linking service users with existing employment schemes and microcredit programmes is recognised as an important strategy for promoting livelihoods (Chatterjee et al., 2009). But it has also been suggested that people with severe mental illness are likely to be systematically excluded from ongoing community development efforts that would enhance their capabilities, due to stigma (Plagerson, 2015) and individual factors stemming from their illness. A practical approach suggested to address this in the short term would be to revise grant administration to enable recipients to invest in their capabilities and go beyond meeting basic household needs (e.g., facilitating access to small business loans, skills training programmes) (Graham et al., 2012). While this does indicate increased investment in the value of the grant, this may not need to be great (Graham et al., 2012) and the benefits it could generate in terms of capabilities, income and household standard of living may far outweigh the costs. The BasicNeeds approach

includes providing access to credit through self-help groups (Cohen et al., 2012). While repayment rates may vary and the approach may not be as effective as is commonly thought (Stewart et al., 2010) this could be another strategy for government and NGOs to use to enable service users to build their capabilities. Rather than seeing those with psychiatric disability as dependent on welfare (grants) and incapable of participating in the economy, new approaches should recognize adaptive capacities, particularly in harnessing opportunities in the informal economy (Duncan, 2009), which would be facilitated by a micro-loan function.

It is also important to recognize, as was noted by the experts consulted in development of the intervention materials, that in their recovery journey some service users may not be able to be employed or involved in income generation. This is both because of their level of functioning in different domains (Lieberman et al., 2008) and because of limited employment opportunities in the economy in South Africa. For those with severe mental illness, aspects of their illness such as feeling hopeless, difficulty making decisions and lack of focus on longer term goals also contribute to challenges in converting capability or income into achievement of a satisfactory standard of living (Burchardt, 2004; Hopper, 2007). This PSR intervention may be further strengthened by focusing on these aspects. Capabilities theory speaks to this challenge in that increasing attention is being paid to investing in the shared capabilities or “collective capabilities” of households, whereby each individual is part of a “network” of support or social capital enabling collective action and individual agency (Dubois & Trani, 2009). Within this framework, people with disabilities can make significant contributions to their households other than through employment or income generation, as evidenced in this study by increased service users’ contributions to household chores (see Paper 3). Improvements in functioning can free up other family members to take up employment opportunities (Graham et al., 2012). Further strengthening of the intervention for direction of productive or income generating

activity towards enhancing “collective capabilities” of households may be beneficial. This would be supported by evidence from a BasicNeeds study in Kenya showing improvements in the “collective capabilities” of households reflected in increases in family income, mediated both by economic activity of those with mental illness as well as reduced caring roles for family members potentially enabling their seeking income generating opportunities (Lund et al., 2013).

2. Individual needs assessment

Secondly, a conceptual tension emerged in terms of the intervention design, in that the provision of a manual-based (i.e., standardized) intervention aiming to support a highly individualised process (recovery) (Lieberman et al., 2008) may be problematic. Rehabilitation and recovery are individual processes and additionally are not straightforward “linear” processes. There may be steps forward, and steps back, as individuals face the challenges of functioning in their environment (Anthony, 2003). Both factors internal to the individual (e.g., avolition) and their environment (e.g., poverty) can work against recovery (Onken et al., 2007). The contrasting perceptions of service users reported in Paper 3 relating to the ‘Knowing Myself’ and ‘Money Management’ sessions highlight this tension and suggest the need for tailoring of the approach to individuals needs to a greater degree. The COPSI intervention in India included an individual structured needs assessment at enrolment and every three months subsequently, and corresponding individualised rehabilitation plans (Chatterjee et al., 2014). Recent developments in task-shared interventions for depression, anxiety and post-traumatic stress disorder (PTSD) (the Common Elements Treatment Approach) also indicate the feasibility of trained lay counsellors implementing a more flexible and needs-based approach to address more than one clinical mental health problem (Murray et al., 2014). Adaptation of this approach for this community-based PSR intervention may be relevant, given the importance of individual needs and the prevalence of co-morbid mental health conditions in

service users with schizophrenia. For example, inclusion of a brief intervention for substance abuse may be relevant, given high rates of abuse in South Africa and among those with severe mental illness. Exclusion of an individual needs assessment may be an important limitation of this intervention but was not possible given the limited human resources for implementing the intervention. It follows that refinement of the intervention to be more flexible and responsive to individual needs, while indicated, is likely to involve significant additional resources in terms of training time and contact time between participants and service providers. However its exclusion may limit the quality of the intervention and provides further impetus for advocating for the appropriate allocation of human resources for community-based PSR, and in further testing of this intervention. An individual needs assessment would also enable addressing physical health needs of service users, a priority for this patient group (Jenkins et al., 2011b; Silove & Ward, 2014) and shown to be a challenge for at least one service user in the study (Paper 3). The additional resource investment would also set the stage for a more active participation of service users in their ongoing treatment and psychosocial support, in line with the adjustment of South African health system towards a Chronic Care Model (Wagner et al., 2005).

Further to this, agency and self-determination are key aspects of recovery in HIC. These aspects are similarly valued in the South African context (Sunkel, 2011; Sunkel, 2014) and have been the basis for evolution of service user movements in Africa (Kleintjes et al., 2013; Kleintjes et al., 2010). Responding to individual needs may be a first step in boosting agency of service users in this context. This is relevant not just for individual agency and empowerment. Service user, researcher, clinician and family advocates are needed to push for progress on appropriate resourcing for mental health services (Hanlon et al., 2010). Anecdotal reports and the experience from this research indicate that service user advocacy is minimal at the district level

of the study, and the only well recognised advocates are at national level. Lack of empowered civil society (including service users) can be a stumbling block in terms of development of appropriate mental health services (Omar et al., 2010). Enhancing capabilities for users to self-advocate therefore also seems to be an important area for intervention development in the future and individualised needs assessment may be a key first step in this direction. This refinement would also bring the conceptual basis of the intervention more strongly in line with capability theory by incorporating the importance of agency and emphasizing enhancing service users' real opportunities for self-determination and participation in society (Burchardt, 2004).

3. Refinement of materials

In terms of the intervention materials, the one refinement necessary would be to remove any activity that involves reading or writing. This was initially thought to be appropriate given that most service users were expected to have primary education. However with the service user group studied would all have grown up with the South Africa apartheid education system given their ages (see Paper 3) this was not appropriate. Anecdotal reports from Facilitators in this pilot study indicated they spontaneously adjusted “tasks” from the Facilitator Guide that involved reading or writing to be appropriate for the group.

Feasibility

Data from this PhD study have shown the overall feasibility of non-specialist workers delivering the PSR intervention in this low-resource context (see Paper 3). The Facilitator Guide specifically was shown to be feasible for use used by trained non-specialists making it a potential resource for use elsewhere in South Africa. The MRC guidance identifies variation

in implementation factors as a key consideration and the corresponding need for clear description of interventions to make them replicable (Craig et al., 2008). The formative evaluation of the intervention (Paper 3) provides a clear account of implementation factors, and additionally the training manual for training non-specialists to implement the intervention is structured such that it gives background and directions that would enable replication of this model in other contexts by a trainer with mental health background. Similarly, the Facilitator Guide is structured to enable replication by trained non-specialists with secondary education, in any South African context. This study has also provided important contextual information that would be valuable in further evaluation including realistic numbers for recruitment and retention in the intervention (Campbell et al., 2007). The PhD study fulfils objectives of a pilot study in that it has identified important barriers for implementation in this context, which are discussed in detail in Paper 3, and which would need to be addressed in further testing.

Adjustments to improve feasibility

1. Requirement for suitable venue

Firstly, the lack of an appropriate venue was a concern to the majority of service users and the group Facilitators and future testing of the intervention could define lack of an appropriate and private space for groups as a factor for exclusion of health facilities (Patel et al., 2011). Alternatively, venues in the local community (e.g., church hall) would also be suitable venues (while linked to clinics, the groups do not need to take place in clinics). However efforts made in the pilot to find such a venue within easy walking distance for service users were unsuccessful, signalling the levels of infrastructure deprivation in the area (see Photograph 1 below).



Photograph 1: View of community from Majara Sepapho clinic

2. Provision of supervision

Secondly, adequate and effective supervision of Facilitators in relation to their role in this intervention was a key challenge. Although a supervision plan was put in place, the supervisor (social worker from MHS) left the organisation during the implementation of the programme (Paper 3). A member of the PRIME team however did provide mentorship through attendance at sessions of the programme, in line with the apprenticeship model for task-shared mental health interventions (Murray et al., 2011). This would not be a sustainable approach to wider scale testing or roll out of the intervention. Staff turnover is well recognised as a challenge to the provision of high quality supervision and support required for task-shared interventions (Murray et al., 2011; Silove & Ward, 2014), fuelled by insufficient staff support and remuneration (Alem et al., 2008). A better defined supervision protocol (Patel et al., 2011) and

further training for supervisors in supportive supervision are suggested in further testing of the intervention. There also needs to be stronger recognition that quality supervision can be costly – it was the most costly aspect of the COPSI intervention (Silove & Ward, 2014). Future costing of the intervention should therefore make provision for this cost and resource requirement as an essential requirement of the intervention. Consideration also needs to be taken of diversification of the role of social workers to encompass supervision and mentoring of lower level workers in a task-sharing approach. This will have implications for job descriptions as well as pre-service training.

3. Caregiver groups

Thirdly, an important limitation of feasibility in this study was that the caregiver group was not successfully formed (Paper 3) due to low levels of participation. The caregiver aspect of this intervention was conceptualised both as a source of support for caregivers, but also with consideration of the biopsychosocial model of disability. For service users in this context who live with family, the most important way to promote a more supportive social environment may be through the family structure itself, particularly by reducing experiences of stigma and discrimination caused by family members and by increasing their understanding of the illness and of coping skills for supporting service users. Although there is evidence that the service user group itself provided a supportive social environment, the lack of formation of the caregiver group is a limitation to the incorporation of the biopsychosocial model. While data from this study indicate that service users do believe family are supportive (Paper 3), conflicts and mistreatment were also evident in formative work (Paper 1). The question remains as to how much real family support is available for service users in this context, and whether their perspectives of family support are clouded by past experience and the belief they deserve no better. This is similar to the example given by Martha Nussbaum of the Indian woman who stayed for many years in an abusive marriage as she believed that this was her “lot” and only

saw this as a violation of her rights after being part of women's self-help groups (Nussbaum, 2001) p. 68 cited in (Burchardt, 2004).

The limitation of this intervention in addressing the social aspect of disability seems to be common in the CBR field. The "CBR Matrix" as promoted in the WHO CBR guidelines emphasizes the need to focus on five components (health, education, livelihood, social and empowerment) to comprehensively address the needs of those with disability (WHO, 2004). However the recent Cochrane review of CBR approaches included only one study that addressed components other than health and education (Iemmi et al., 2015). This PSR intervention seems to adequately address the health and education components of the CBR matrix, and the livelihoods and empowerment components were discussed above. The social component may be improved through greater effort at ensuring the establishment of caregiver groups. More extensive mobilisation and engagement, requiring additional inputs of ASW time than were feasible in this pilot, are indicated since informal feedback from Facilitators was that with more time spent with families and in the community they felt they would be able to successfully form caregiver groups. In the long term, as services for PSR develop, interventions to promote social inclusion through reducing stigma and discrimination from the wider community may be an important component drawing on learnings from interventions based on social contact between service users with mental illness and those without mental illness [e.g., (Evans-Lacko et al., 2012)]. Context appropriate strategies for promoting social contact should be leveraged, for example extended family networks, burial societies, savings groups and other group organisations specific to local communities.

The resourcing issue – a crucial concern for PSR service delivery and sustainability

The preliminary benefits identified, as well as evidence for acceptability and feasibility demonstrate the potential of this intervention. It seems to be a promising approach that warrants further investigation with “exploratory and definitive evaluations” (Craig et al., 2008), p 980. However, a consistent finding that has emerged from this pilot study is the need for additional resources (predominantly in the form of ASW and supervisor time) to improve both acceptability and overall feasibility of this PSR intervention (see Paper 3). The challenge of resource allocation for PSR and other community mental health services is not new, however little progress seems to have been made in South Africa, specifically for PSR. The intractability of this resourcing issue was ever present in the minds of the PRIME team and myself as lead researcher on this intervention through the process of the intervention development, and the engagement with DOSD and the MHS described. It was for this reason that a portion of the research of this PhD (Paper 4) focuses on the intersectoral collaboration required for feasibly addressing this resourcing issue and providing PSR services at a wide scale in the country. Further discussion on this is in the following section relating to Paper 4.

Sustainable provision of PSR – the role of intersectoral collaboration

The challenge of sustainable resource provision and lack of progress on intersectoral working for PSR, as identified through the advocacy and engagement work underpinning Paper 3, was investigated in Paper 4. South Africa is not alone in grappling with this complex challenge. The lack of resources for mental health in LMIC is well known and lack of intersectoral

collaboration (which can be leveraged to provide resources for mental health) has been identified as a key impediment to implementing community mental health in Africa (Hanlon et al., 2010). There are however documented examples of how a long-term and intersectoral working process can promote an integrated and sustainable approach to mental health services. For example in Kenya, a research and policy development process for mental health services spanning 10 years included involvement (in training, policy and service development) of multiple stakeholders (e.g., departments for police, prisons, schools, social welfare, health) from the outset (Kiima & Jenkins, 2010).

Participants in this PhD study identified several strategies for addressing challenges to sustainable intersectoral working for provision of PSR (detailed in Paper 4). These included *inter alia*:

(i) *Promoting sector fulfilment of roles* under Mental Health and Social Development policies.

This would mean improved collaborative roles between relevant actors at district level particularly. In terms of the DOH role the key function this sector would provide would be leadership on provision of PSR services, through involvement of primary care workers in a modified “case management” role. The need for this was emphasized to ensure continuity of quality care for service users. The role emphasized for DOSD was in incorporating service users with mental illness into their overall community development approach, both by broadening the reach of infrastructure and services for community development and reducing the exclusion of people with psychosocial disability from existing community development efforts.

(ii) *Improving communication and formalised work agreements* between the sectors and strengthening leadership from DOH was indicated. Social Development Clusters were

identified as the key structure for communication and action on issues relating to PSR services. While these clusters seem to be functional at national and provincial level, their existence and effectiveness at district level was questioned, and similarly service level agreements between intersectoral partners were absent. These represent two practical areas for improvement, which could be spearheaded by the proposed district specialist mental health teams.

(iii) *Direction of the resources that are available to community level* was an area of need that was recognised to be crucial but on which progress was slow and complex. The most discussed need was for the provision of infrastructure and management for community residential facilities. The need for resource allocation does however cross over to other areas of community-based services, including appropriate funding of NGOs and other service providers for the task-shared psychosocial interventions called for in the National Mental Health Policy Framework and Strategic Plan.

This data from Paper 4 has contributed practical recommendations for improving intersectoral collaboration for PSR in South Africa, which may have implications on the resourcing of services for community-based PSR. In an effort to ensure that this evidence is turned to action, these recommendations will be incorporated into a policy brief based on Paper 4 as an advocacy tool directed at policy makers and programmers specifically at the provincial and district levels in South Africa. Evidence in this study suggests these are the key areas where action on intersectoral collaboration is required. A photo-essay involving service users from the PSR group in this pilot showcasing some of its benefits has also been created by PRIME for use as an advocacy tool.

While Paper 4 provides recommendations that can be taken up by NGOs, DOSD and DOH at district and provincial level, there needs to be a change in the overarching view of government and civil society to bring the concerns of psychosocial disability firmly into the development agenda. Sen himself in his original conceptualisation of how the theory of capabilities could contribute to development called for progress from different directions (Sen, 1999). Strengthening programmatic links between health (and mental health) and social and economic development builds on the capabilities approach – since bringing together the challenges of development, poverty and disability effectively means enhancing capabilities (Graham et al., 2012). What is needed is not only more resources (which should be advocated for, but which may always be lower than what is needed) but “careful strategic dialogue and action” (Jenkins et al., 2011c), p 87, between sectors. This relates to shifting the status quo of government departments (notably DOH and DOSD) from working in “silos” and competing for scarce resources (Paper 4).

These challenges can be addressed conceptually by revisiting the links between the fields of social development and health, with mental health as a strategic cross-cutting issue. The vicious cycle of poverty and mental ill health is well recognized, at least by those working in the mental health sphere (Lund et al., 2011), however the societal and economic benefits of improving mental health are not well researched in LMIC (although they are likely to be significant, as is evident from HIC) (Plagerson, 2015). The lack of recognition then of the potential for a “virtuous cycle” (i.e., positive impact of good mental health on social development and vice versa) means that mental health (and notably the impact of severe mental illness) is often not tied specifically to the Governmental social development agenda (e.g., Poverty Reduction Strategy Papers) (Jenkins et al., 2011c). More broadly, although disability movements may be gaining traction, people with disabilities are often excluded from development plans for

reducing poverty and inequality, despite their high representation in the numbers of those most affected by these linked disadvantages (Graham et al., 2012).

While much of the impact of NGO work linking mental health and economic development may be undocumented in peer reviewed journals, two recent studies have shown the feasibility of the Basic Needs Model for Mental Health and Development (incorporating non-specialist delivered social support) in Kenya in both improving mental health and integrating economic empowerment (Lund et al., 2013). The model has also been shown to be cost effective and equitable (de Menil et al., 2015). These evaluations provide evidence that the issues of mental health and social development can be feasibly and jointly addressed (by NGOs) in low resource contexts, which should encourage governments of other LMIC such as South Africa to direct attention to this issue and work towards appropriate funding of NGOs to extend these services. The authors of these evaluations however note a key concern in that more than 80% of the direct costs of the programme are NGO financed (i.e., donor funded), unsustainable, and prohibitively high for Kenyan governmental provision (de Menil et al., 2015). This brings into sharp focus the key challenge for intersectoral provision of PSR. While NGOs are ideally placed to provide such services (Rangaswamy & Sujit, 2012; Silove & Ward, 2014), donor funding is unlikely to ever be a feasible large-scale and sustainable approach for country wide services (Jenkins et al., 2011a). The Kenyan policy and service development example cited documented a critical success factor in that it did not rely on externally funded services but instead leveraged multisectoral collaboration to enable service provision through “regular ministry budgets” (Kiima & Jenkins, 2010), p 8. Similarly, calls were made by participants in this PhD study for DOSD to fund a wider network of NGOs to provide PSR services and this model of service provision was well accepted by participants in this study. The redirection of funds from DOH following deinstitutionalisation processes would also be needed to

significantly bolster these resources. The technical and financial complexities of operationalising this are an important topic for future investigation. Some costing data for services for people with severe mental illness does exist in South Africa (Lund & Flisher, 2006; Lund et al., 2001) but this does not include community residential or rehabilitation services. The investments required to provide adequate care for service users with schizophrenia are not insignificant (e.g., estimated at USD177 per patient per year in India, and likely to be higher in South Africa where health service costs are higher) (Patel, 2015). These costs however need to be viewed through the lens of their potential economic contributions (e.g., through increased earnings of service users, caregivers and households) (Patel, 2015) instead of simply as gains to health outcomes of individuals with schizophrenia. While the barriers to resource allocation in this way are significant, experience of some countries (e.g., Brazil, China) indicates that political commitment, availability of “transitional” finances for the initial set up of services and alignment to an intersectoral service provision approach can enable progress (Patel, 2015). In particular, Brazilian experience showed from 2006 onwards government spending on mental health increasingly focused on non-hospital services. Between 2001 and 2009 spending on community mental health services increased by 354% per capita, compared with a 45.5% increase in hospital services (Gonçalves et al., 2012). This increase reflects not only redirection of hospital funds to the community, but also increased overall investment in community services (Gonçalves et al., 2012).

Implications for policy makers

It is not only a lack of evidence that hampers provision of services for mental health, but a lack of leadership, commitment and intersectoral action (Saraceno et al., 2007; Skeen et al., 2010; Tomlinson & Lund, 2012). While it seems that at the national level the leadership required for

progress on provision of PSR is present, capacity building and technical support are required (as well as financial commitment) to implement policy directives (Marais & Petersen, 2015). Specific recommendations for policy makers/implementers on implementing policy directives for community-based PSR at the provincial and district level will be included in the Policy Brief mentioned previously. However there remain three key areas that national level policy makers can address. Firstly they can encourage the adoption of evidence-based approaches for PSR, based on emerging evidence from this study and other LMIC studies. Given the potential cost of implementing PSR country wide in South Africa and the consequent significant injection of resources that would be required, a robust experimental evaluation of the task-shared PSR approach reported in this PhD is recommended, after further piloting. Policy makers from the Health and Social Development sectors would be key in supporting this through provision of sustainable human resources for implementation. Secondly, policy makers at all levels can foster effective intersectoral collaboration for PSR, including through the recommendations outlined in Paper 4, but most specifically through designating budget and human resource capacity to build a platform for intersectoral collaboration with long term vision of universal coverage of PSR. This platform may also have benefits for other cross-cutting health and social development issues. Thirdly, and perhaps most importantly, it is crucial that from the national level, an appropriate model for direction of resources to community level for provision of PSR services in the South African context is developed. This may draw on the experiences of other middle income countries such as Brazil, and China which has instituted a programme for integrating hospital and community-based care for psychoses, which now covers four million patients (Ma, 2012; Patel, 2015). Particular attention will need to be given to “transitional or dual funding” needed to build up community services to effectively support service users relocated from long-stay institutions (Patel, 2015). The overall picture presented by the evidence from this PhD study has provided clear evidence of the need

to do this. As a middle income country, South Africa should be able to designate funds from tax revenue for this type of service (Patel, 2015). Policy makers particularly at national level will need to be the advocates who push to allocate funds to this area of service delivery given multiple competing health priorities. However, given the many other health and development challenges South Africa faces, donors may also have a key role to play in providing transitional funding.

Implications for PSR practitioners

Publications in this PhD study have given recommendations for improving acceptability and feasibility of psychosocial interventions for schizophrenia in low-resource contexts, which may be of relevance to PSR practitioners in South Africa and elsewhere. The most important implication for PSR practitioners is the need for their focus to link strongly to the needs of service users they work with. A recent Chinese study showed people with schizophrenia living in rural areas to be more likely to be employed (e.g., in farming and fishing) than those in urban areas despite having lower access to treatment (Yang et al., 2013). This highlights that needs and services provided may vary greatly within countries and regions. PSR practitioners should respond to this through appropriate assessment of and response to needs of individual service users, as discussed previously. Particular attention will need to be given in the South African context to provision of appropriate services in rural areas given the current lack of services in these areas. A further implication of the results of this study for PSR practitioners is the need to take a broad focus on entire families in the provision of PSR, similar to that of family social work. In this way a service user with schizophrenia would be seen as one part of a family, having their own specific needs, with other family members, particularly primary caregivers, having their own set of needs. The aim would be to work with families to create an environment

that is supportive for all members and provides opportunities for enhancing collective capabilities and reducing the impact of poverty and disability on entire families. PSR practitioners in South Africa specifically also have an important role going forward in working with service users and families to strengthen service user and caregiver advocacy to advocate for adequate service provision in all provinces and districts – providing another push for appropriate resource allocation.

Limitations

Evidence from this study is limited in several ways as discussed specifically in Papers 1-4. These limitations relate to the small sample size of the PSR group formed, and reliance on qualitative methods for assessment. However these approaches are consistent with the initial phases of MRC framework (Craig et al., 2008). Overall the study was limited by not assessing objective measures of illness severity and disability (e.g., symptoms, functioning). Conceptually the intervention has several limitations. Firstly, working in a low resource environment and with a task-sharing approach, one limitation of this work is that it did not investigate psychosocial/ psychotherapeutic interventions that require more specialised psychological staff (e.g., cognitive remediation), even though there is likely a role for these interventions in the South African context (Midin et al., 2011) in more well-resourced settings where the required human resources are available. Secondly, collaboration with traditional and spiritual leaders has been identified as important to rehabilitation in Africa (Alem et al., 2008), however traditional healers were not specifically engaged in the approach. The main reason for this was that the health system structures (i.e., PHC clinics) and NGO (Mental Health Society) that were the structures for implementation of this study are themselves not systematically working with traditional healers. Thirdly, although drawing on the social model of disability,

the intervention does not address the “systematic exclusion” of those with psychosocial disability from society (Burchardt, 2004) through addressing stigma and discrimination, so while the intervention is focused on improving individual factors for recovery, the influence on environmental factors is lacking. Broad social level interventions aiming to reduce stigma are recognised as a need for future work in South Africa as elsewhere.

Future Research

This study indicates some important areas for future research. A systematic assessment of the intervention, following the later stages of the MRC Framework or other frameworks for implementation science in health (e.g., the QUERI framework) is indicated. This process would involve further piloting with an experimental design, including quantitative measures of symptoms and disability, followed by a rigorous larger scale effectiveness trial, including economic outcomes and data on cost effectiveness. Further evaluation should be tailored to locally relevant and valued social outcomes for example through conducting Focus Group Discussions with service users, providers and family members (Chatterjee et al., 2009) as well as further adaptation of research processes (e.g., consent procedures) (Chatterjee et al., 2015) to improve acceptability and participation. Beyond a locally relevant functional assessment of the type developed by Bolton and colleagues (Bolton & Tang, 2002), leaning towards a capability approach would suggest assessing what each individual and household/family is capable of in their environment and able to achieve rather than looking just at their level of functioning (Welch Saleeby, 2006). Research into the health system issues identified in this study (e.g., medication supply, referrals) is also indicated, particularly supply chain management of drugs and the referral processes between primary, secondary, and tertiary care (Hanlon et al., 2010) for severe mental illness in South Africa to identify where service users

are “falling through the cracks” and implement measures to resolve this. Medication supply issues in particular would need to be investigated as non-adherence to medication due to unavailability could have an important detrimental impact on estimations of effect in reductions of symptoms and disability, hampering an effectiveness trial. Lack of regular medication supply could also discourage service user and family participation in programme (Srinivasa Murthy et al., 2005).

Conclusion

This PhD study has contributed new knowledge and experience relating to the development, piloting and preliminary qualitative outcomes of a task-shared PSR intervention for a low-resource South African context. The study has been guided by the MRC framework for design and evaluation of complex interventions (Craig et al., 2008) and has provided significant grounding for further testing of the intervention through a randomised controlled trial. The evidence for acceptability and feasibility of the intervention support this testing, however they also point to the crucial need for appropriate allocation of further resources given that no PSR service delivery platform currently exists in many areas of the country. Given the current barriers to funding wide-scale community-based PSR, a great drive of political will is likely to be needed to accomplish this end (Eaton et al., 2011; Saraceno et al., 2007). This can only be fuelled by a growing awareness by leadership in particularly the Health and Social Development sectors that in South Africa, as in other LMIC, people with schizophrenia living in conditions of poverty remain some of the most marginalised in our society. A “moral transformation” (Kleinman, 2009), p 603, is needed to move towards social justice and health equity for this vulnerable group.

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Appendix 1 Schizophrenia Leaflet

Schizophrenia



Where can I find help?

At your local clinic or hospital

At the Mental Health Society in your area

LIFELINE 018 462 1234

SABDA (Schizophrenia and Bipolar Disorders Alliance)

national helpline 011 326 0061

What is schizophrenia?

- Schizophrenia is a serious and lifelong mental illness.
- Someone with schizophrenia may behave in an unusual way, hear or see things that are not there, and have difficulty concentrating.
- This can cause difficulties in relationships with family and friends and in keeping a job.
- Someone with schizophrenia may have times when they are well and times when their illness becomes more severe (relapse).

What causes schizophrenia?

It is not known exactly what causes schizophrenia. It is most likely a combination of factors including:

- family history of schizophrenia;
- brain chemistry or an injury to the brain;
- environment and personal life experiences;
- if a person is vulnerable to the illness there are factors that make it more likely that the illness will develop; and
- examples of these risk factors could be loss of a job, divorce, poverty, difficult relationships, and problems at work, home or school, drug and alcohol abuse.

How will I know if I have schizophrenia?

A doctor or psychiatrist diagnoses schizophrenia.

Symptoms of schizophrenia include:

- false beliefs (e.g. thinking others are trying to harm you);
- hearing voices that are not there;
- inappropriate emotions (e.g. laughing at something sad);
- loss of social skills;
- restlessness, walking up and down; and
- aggression.

How to manage your illness

MEDICATION Always take your medication as instructed. Your doctor may prescribe a regular injection rather than tablets. Ask a family member to remind you to take your medication. Manage side effects.



Learn what triggers your relapses – like not getting enough sleep, stress, misusing alcohol or drugs. Learn your early warning signs – feeling tense, depressed, irritable or becoming forgetful. Go to the doctor or hospital before you have a relapse.

Eat a healthy diet, exercise, sleep and avoid stress. Get involved in your community, make time for socializing and relaxation. Join a rehabilitation group for people with schizophrenia in your area.



Psychosocial rehabilitation can help a person cope better in relationships, improve their daily functioning and work and become integrated into their community like any other person.

Join us at your nearest clinic for support. Talk to your nurse about the support and care you can get at your clinic to help you in your treatment.



Schizophrenia



Ke ka bona thuso kae?

Ko kokelwaneng kana kokelo ya gago

Ko Mental Health Society mo tikologong ya gago

LIFELINE 018 462 1234

SABDA (Schizophrenia and Bipolar Disorders Alliance)

national helpline 011 326 0061

Schizophrenia ke eng?

- Schizophrenia ke botlhoko jwa tlhologanyo jo bo tseneletseng ebile e le ja botshelo botlhe.
- Mongwe yo nang le schizophrenia o nna le maitshwara a sa tlwaelegang, a bona le go utlwa dilo tse di seyong, a sa kgone go baya tlhologanyo ya gagwe mo selong se le sengwe.
- Se se tlhola mathata mo tirisanyong le ba lelapa, ditsala le go ka nna le tiro.
- Mongwe yo nang le schizophrenia o ka nna le dinako tse a ikutlwang sentle, le dinako tse bolwetsi/botlhoko bo mo gatelelang (bo boa gape).

Ke eng se se tlohang schizophrenia?

Go go itsewe gore ke eng sentle sentle se setlohang schizophrenia. Gantsi e ka nna kakaretso ya dintlha tse di tsenyeletsang:

- Fa go nale mongwe yo o kileng a nna le schizophrenia mo go ba lelwapa
- Boboko bo sa dire sentle kana bo nnile le kgobalo
- Tikologo le diragalo tsa botshelo
- Fa motho a sa babalesega mo bolwetseng jo go nale mabaka mangwe a ka bo etlegetsang.
- Dikai tsa di lo tse e ka nna go latlhegelwa ke tiro, tlhalano, botlhoki, botsalano jo bo sa nnang sentle, mathata a ko tironng, ko gae kana ko sekolong le tiriso ee botlhaswa ya bojwala/dithitifatsi

Ke ka itse jang fa ke nale schizophrenia?

Ngaka kgotsa psychiatrist o ka tlhomamisa schizophrenia. Matshwao a schizophrenia a balela:

- Ditumelo tse di sa netefatswang e.g. o gopola fa bangwe ba batla go go ntsha kotsi
- go utlwa mantswe a a seyong
- Maikutlo a a sa tsamaelaneng le se se diragalang e.g. go tshaga sengwe se se botlhoko
- Go latlhegelwa ke go dirisanya sentle le batho ba bangwe
- Go tlhoka go nna fela, o tsamaya kwa lekwa le
- Go nna mahega kana go batla go lwa.

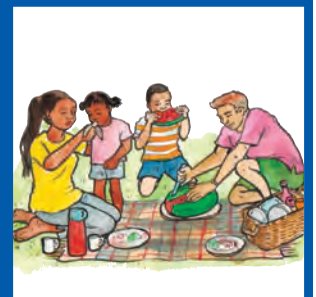
O LAOLA JAANG BOLWETSI/BOTLHOKO?

DITLHARE Tsaya ditlhare tsa gago ka nako tsothe jaaka o laetswe ke ngaka ya gago. Ngaka o ka go laela go tsaya lemao ka metlha le metlha go nale dipilisi. Kopa mongwe wa leloko la gago g ogo gopotsa kgotsa g ogo thusa go tsaya ditlhare tsa gago. Ngaka e tla g o thusa go laola ditlamorago tsa ditlhare.



Ihute gore ke eng se se tsosang go lwala thata, jaaka go sa robale sentle, go nagana thata, tiriso e botlhaswa ya bojwala le dithitifatsi. Ihute matsHwao a tsibiso jaaka go ikutlwa o gagametse mmele, o gateletswe mo maikutlong, o tenega ka pela kgotsa go lebala. Eya kwa ngakeng kgotsa bookelo pele ga bolwetsi bo tsoga gape.

Ja dijo tse di itekanetseng, itshidile gangwe le gape e bile o robale, o ikitse go tshwenyega mo maikutlong. Leka go kopana le batho mo motseng, mme o dire nako ya go iketla le go tsalana le batho ba bangwe. Tsenela setlhopa sa batho ba ba nang le schizophrenia (support group) mo tikologong ya gaeno.



Dithuto le thotoetso tsa psychosocial di ka thusa motho go tokafatsa ka fa a tsalanang ka teng le batho ba bangwe, ditiro tsa gagwe tsa le tsatsi le letsatsi, tiro ya gagwe le go kgona go tsena mo sechabeng jaaka mongwe le mongwe.

Re bone mo kokelwaneng e gaufi le wena go bona thuso. Bua le mooki ka thuso le tlhokomelo tse o ka di bonang ko kokelwaneng ya gago go thusa pholo ya gago.



Appendix 2 Ethical Clearance



01 August 2012

Mrs Carolyn Brooke-Summer 212559195
School of Psychology

Dear Mrs Brooke-Summer

Protocol reference number: HSS/0623/012D
Project title: Psychosocial Rehabilitation for Schizophrenia: Developing A Community-Based Self-Help Approach to Promote Recovery in Dr Kenneth Kaunda District, North West Province

EXPEDITED APPROVAL

I wish to inform you that your application has been granted Full Approval through an expedited review process.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number. Please note: Research data should be securely stored in the school/department for a period of 5 years.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

Professor Steven Collings (Chair)

/px

cc Supervisor Professor Inge Petersen
cc Academic leader Professor JH Buitendach
cc School Admin. Ms Nondumiso Khanyile/Ms D Huttingh

Professor S Collings (Chair)
Humanities & Social Sc Research Ethics Committee
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban, 4000, South Africa
Telephone: +27 (0)31 260 3587/8350 Facsimile: +27 (0)31 260 4609 Email: ximbap@ukzn.ac.za / snymanm@ukzn.ac.za
Founding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville

Inspiring Greatness



Appendix 3: Informed consent forms

Service Users Informed Consent Form for formative interviews (Paper 2)

Study Information Sheet

The Research Study

We are asking you to participate in a qualitative study of the health and mental health services in the Dr Kenneth Kuanda district. The study will be conducted by researchers from the **PR**ogramme for **I**mproving **M**ental Health **C**ar**E** in South Africa (PRIME-SA) which is a collaboration between the universities of KwaZulu-Natal, Cape Town and the Department of Health.

What are we trying to learn?

In this research we are wanting to find out about provision of psychosocial rehabilitation for people with chronic mental illness in the Dr Kenneth Kuanda district.

Why is it important?

This study is important so that it can inform the development of a district mental health plan which will comprise integrated packages of care for psychotic disorders, amongst other mental illnesses.

What will it mean if you participate in the study?

If you agree to participate in this study you will be asked to answer a number of questions about your experiences in relation to rehabilitation for your mental illness. This information will be used to inform the development of an appropriate intervention plan for the district.

Is there any disadvantage from participating in this study?

There are no disadvantages from participating in this study.

What if I change my mind later?

You are free to withdraw at any stage from participating in the study and your decision will not disadvantage you in any way.

Who will see the information that we collected?

All records will be kept completely confidential. Your identity will be anonymous and only aggregate data reported.

Who to contact if you want to know more, or if you have a problem at any time?

If you want more information on the study before deciding whether or not to participate, or if you participate and later need help or have questions, please contact:

Prof I. Petersen

School of Psychology

University of KwaZulu-Natal

Tel: 031 260 7970

If you wish to know more about your rights as a participant in this study you can contact:

Ms Phumelele Ximba, Research Office, University of KwaZulu-Natal.

Tel: 2603587

Consent to Enroll

I, _____ agree to participate in the study on psychosocial rehabilitation in the Dr Kenneth Kuanda district to help develop a mental health plan for the district. I have received and understood the study information sheet. I have discussed the advantages and disadvantages of participating in the study and I agree to participate in the interview as stated in the information sheet.

I know I can leave the research study at any time without prejudice.

Signature: _____

Name: _____

Date: _____

Witness 1

Signature: _____

Name: _____

Date: _____

Witness 2

Signature: _____

Name: _____

Date: _____

You may keep the information sheet. The signed consent form will remain in our study files.

Caregivers Informed Consent Form for formative interviews (Paper 2)

Study Information Sheet

The Research Study

We are asking you to participate in a qualitative study of the health and mental health services in the Dr Kenneth Kuanda district. The study will be conducted by researchers from the **PR**ogramme for **I**mproving **M**ental Health **CarE** in South Africa (PRIME-SA) which is a collaboration between the universities of KwaZulu-Natal, Cape Town and the Department of Health.

What are we trying to learn?

In this research we are wanting to find out about provision of psychosocial rehabilitation for people with chronic mental illness in the Dr Kenneth Kuanda district.

Why is it important?

This study is important so that it can inform the development of a district mental health plan which will comprise integrated packages of care for psychotic disorders, amongst other mental illnesses.

What will it mean if you participate in the study?

If you agree to participate in this study you will be asked to answer a number of questions about your experiences in caring for a person with mental illness. This information will be used to inform the development of an appropriate intervention plan for the district.

Is there any disadvantage from participating in this study?

There are no disadvantages from participating in this study.

What if I change my mind later?

You are free to withdraw at any stage from participating in the study and your decision will not disadvantage you in any way.

Who will see the information that we collected?

All records will be kept completely confidential. Your identity will be anonymous and only aggregate data reported.

Who to contact if you want to know more, or if you have a problem at any time?

If you want more information on the study before deciding whether or not to participate, or if you participate and later need help or have questions, please contact:

Prof I. Petersen

School of Psychology

University of KwaZulu-Natal

Tel: 031 260 7970

If you wish to know more about your rights as a participant in this study you can contact:

Ms Phumelele Ximba, Research Office, University of KwaZulu-Natal.

Tel: 2603587

Consent to Enroll

I, _____ agree to participate in the study on psychosocial rehabilitation in the Dr Kenneth Kuanda district to help develop a mental health plan for the district. I have received and understood the study information sheet. I have discussed the advantages and disadvantages of participating in the study and I agree to participate in the interview as stated in the information sheet.

I know I can leave the research study at any time without prejudice.

Signature: _____

Name: _____

Date: _____

Witness 1

Signature: _____

Name: _____

Date: _____

Witness 2

Signature: _____

Name: _____

Date: _____

You may keep the information sheet. The signed consent form will remain in our study files.

Service Users Informed Consent Form for formative evaluation (Paper 3)

Information Sheet and Consent for Service Users

To participate in a study to evaluate the PRIME-SA psychosocial rehabilitation programme

You will be given a copy of this information sheet

Date:

Dear Service User,

My name is Palesa Mothibedi from the PRIME (Programme for Improving Mental Health Care) project at the University of KwaZulu-Natal in Durban, South Africa. My office is in Klerksdorp and I can be contacted on 0871351613. The director of this project is Professor Inge Petersen. She is based at UKZN in Durban and can be contacted on 031 260 7970 or peterseni@ukzn.ac.za. The PRIME-SA project and the current study are funded by the Department of International Development (DFID) in the United Kingdom.

You are being invited to participate in a study that involves research about the programme for psychosocial rehabilitation for people with schizophrenia and their caregivers. Before agreeing to take part in this research study, please read the information below so that you understand what the study will involve. Please read this carefully and feel free to ask me if there is anything that is not clear or if you have any questions about your participation.

What is the purpose of this study?

The aim of this research study is to evaluate how the programme we have implemented is working and to understand the reasons why people did not attend the programme. The goal of this programme was to improve the quality of life for people with schizophrenia and their caregivers. We want to learn what worked and what didn't work so that we can improve on any issues that may have interfered with the implementation of the programme.

Who are we asking to participate?

We are looking for participants who are people with schizophrenia, over 18 years of age and planning to stay in the area for the next month to take part in the study. We are looking for participants in the the Kanana Township outside of Klerksdorp in the Dr Kenneth Kaunda district of the North West province.

What will participation in the study involve?

If you decide to participate in this study, the duration of your participation will be approximately 20-40 minutes, during which you will be asked a number of questions about your experience of being contacted to join the programme and other issues relevant to the programme. The interview will be conducted by myself. With your permission, I will audiotape the interview and the audio recordings will be transcribed later. The audio recordings will be deleted as soon as they have been transcribed.

Will my information remain confidential?

Yes. Should you agree to take part in the study, all your records will be seen by the study researchers only. Information and results of the study that are shared with other researchers will

not contain any identifiable (personal) information such as names or contact details. Every effort will be made to keep your information confidential.

The transcript from your interview will be stored on a computer and protected with a password. The audio recording of your interview, if you consented to it being recorded, will be destroyed immediately after it has been transcribed. Your interview data will be stored under password protection for up to five years on the PRIME-SA computers.

What are the possible benefits of participating in this study?

There are no direct benefits to you for participating in this study. You will be asked to give 20-40 minutes of your time in participating in this study. You will receive no remuneration for your time. We hope that the study results will help us to improve the programme in your community so that services for people with schizophrenia and their caregivers will be improved. The information that we get from this study will also help us to identify any issues that need to be addressed before we implement the new programme in other areas.

What are the possible drawbacks or discomforts of participating in this study?

The only cost to you of participating in this study is your time. If you agree to participate in this study, you will be asked a number of questions about your experience that should take approximately 20 to 40 minutes of your time. If you experience any discomfort or distress during the course of this interview, related to your condition or to the service you received at your clinic, you can contact (name of independent psychologist / counsellor in the area) to speak about your concerns.

Do I have to participate in this study?

It is your choice whether you want to participate in this study or not. If you decide not to participate, you will not be prejudiced in any way. If you decide to take part, you are still free to withdraw from the study at any time and without giving a reason. Should you decide not to take part, or if you withdraw from the study, this will in no way affect the care you or your family member receive at the clinic. Should you agree to participate, we will ask you to sign the attached consent form.

This study has been ethically reviewed and approved by the UKZN Biomedical research Ethics Committee (approval number HSS/0623/012D).

In the event of any problems or concerns/questions you may contact the head researcher, Inge Petersen on 031 260 7970 or the UKZN Biomedical Research Ethics Committee, contact details as follows:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001

Durban

4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604769 - Fax: 27 31 2604609

Email: BREC@ukzn.ac.za

Consent Form for Service Users

Participation in the study to evaluate the PRIME-SA psychosocial rehabilitation programme

Please complete this form after you have been through the information sheet and understand what your participation in this study entails.

Thank you for considering taking part in this study. If you have any questions arising from the information sheet, please ask before you decide whether to take part. You will be given a copy of the information sheet and consent form.

I, (write your name here), _____ have been informed about the study to evaluate the PRIME-SA mental health care programme conducted by Professor Inge Petersen and One Selohilwe.

I understand the purpose and procedures of the study.

I have been given an opportunity to ask questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any treatment or care that I would usually be entitled to.

I have been informed about any available compensation or medical treatment if injury occurs to me as a result of study-related procedures.

If I have any further questions or concerns or queries related to the study, I understand that I may contact the researcher at 031 260 7970 or peterseni@ukzn.ac.za.

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001

Durban

4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604769 - Fax: 27 31 2604609

Email: BREC@ukzn.ac.za

Please tick
or initial

I understand that if I decide at any time during the study that I no longer want to take part, I can notify the researchers and withdraw without having to give a reason.

I consent to the processing of my personal information for the purposes explained to me.

I agree to my interview being audio recorded

I agree that the research team may use my data (information) for future research and understand that any such use of identifiable data would be reviewed and approved by a research ethics committee. In such cases, as with this project, data would not be identifiable in any report.

Signature of Participant

Date

Signature of Witness
(Where applicable)

Date

Signature of Translator
(Where applicable)

Date

Service Providers Informed Consent Form for formative evaluation (Paper 3)

APPENDIX A

Information Sheet and Consent for Service Providers

To participate in a study to evaluate the PRIME-SA mental health care programme

You will be given a copy of this information sheet

Date:

Dear Service Provider,

My name is One Selohilwe from the PRIME (Programme for Improving Mental Health Care) project at the University of KwaZulu-Natal in Durban, South Africa. My office is based in Klerksdorp and I can be contacted on 0871351613 or selohilwe@ukzn.ac.za. The director of this project is Professor Inge Petersen. She is based at UKZN in Durban and can be contacted on 031 260 7970 or peterseni@ukzn.ac.za. The PRIME-SA project and the current study are funded by the Department of International Development (DFID) in the United Kingdom.

You are being invited to participate in a study that involves research about the mental health care programme implemented at your primary health care clinic that is aimed at improving the identification and management of depression and alcohol misuse in patients with chronic conditions. Before agreeing to take part in this research study, please read the information below so that you understand what the study will involve. Please read this carefully and feel free to ask me if there is anything that is not clear or if you have any questions about your participation.

What is the purpose of this study?

The aim of this research study is to evaluate how well the programme that has been implemented at your clinic is working for you as health care providers and counsellors, and for the patients at your clinic who have been involved in the programme. The goal of this programme was to improve the identification and management of depression and alcohol misuse in patients with chronic conditions, including HIV/AIDS. During this programme, we used new guidelines to train nurses in identifying and referring patients with depression to the counseling service at your clinic, and we trained the counsellors to help patients who were found to be suffering from depression.

The study we are asking you to participate in now is to test how well this programme is working. We want to learn what worked and didn't work in the testing of the new programme so that we can improve on the training provided to health care providers and counsellors, the training materials, the supervision and support provided, the quality of care provided to service users and any systems issues that may have interfered with the implementation of the intervention.

Who are we asking to participate?

This study will be taking place at four primary health care clinics, including yours, in the the Kanana Township outside of Klerksdorp in the Dr Kenneth Kaunda district of the North West province. Participants will include the facility manager, primary health care nurses trained in PC101+, primary health care doctors, HIV counsellors trained in the depression counselling guidelines and patients who have been identified as having depression or alcohol use disorder and who were referred by the primary health care nurse to the doctor and/or counsellors. We would like to include in this study all

the primary health care personnel exposed to the PC101+ and counselling training at each facility, as well as a range of patients. We aim to include between 12 and 20 primary health care staff and counsellors from each clinic.

What will participation in the study involve?

If you decide to participate in this study, the duration of your participation will be approximately 20-40 minutes, during which you will be asked a number of questions about your experience of the training you received in diagnosing, referring or treating depression and alcohol misuse, as well as your experiences of how well the programme worked or did not work at your clinic. The interview will be conducted by myself. With your permission, I will audiotape the interview and the audio recordings will be transcribed later. The audio recordings will be deleted as soon as they have been transcribed.

Will my information remain confidential?

Yes. Should you agree to take part in the study, all the information collected from you will be seen by the study researchers only. Information and results of the study that are shared with other researchers will not contain any identifiable (personal) information such as names or contact details. Every effort will be made to keep your information confidential. Although we will try to conduct this interview in a private room, it might happen that, during the course of your interview, another clinic staff member or patient comes into the room. We are unable to guarantee the confidentiality of your participation in this study should this happen. The possibility also exists that, despite the absence of identifying data, the clinic could be identified as the research site due to a process of deduction from the public information about the PRIME project. This does not mean that you yourself will be identified but that the aggregate data from the study may be linked back to your facility.

The transcript from your interview will be stored on a computer and protected with a password. The audio recording of your interview, if you consented to it being recorded, will be destroyed immediately after it has been transcribed. Your interview data will be stored under password protection for up to five years on the PRIME-SA computers.

What are the possible benefits of participating in this study?

There are no direct benefits to you for participating in this study. You will be asked to give 20-40 minutes of your time in participating in this study. You will receive no remuneration for your time. We hope that the study results will help us to improve the programme at your clinic so that service provision and treatment for patients with depression and alcohol misuse will be improved. The information that we get from this study will also help us to identify any issues that need to be addressed before we implement the new programme in other primary health care clinics.

What are the possible drawbacks or discomforts of participating in this study?

The only cost to you of participating in this study is your time. If you agree to participate in this study, you will be asked a number of questions about your experience of the PC101 and counselling training, and about your experiences in implementing the programme at your clinic. The interview should take approximately 20 to 40 minutes of your time. If you experience any discomfort or distress during the course of this interview, you can contact (name of independent psychologist / counsellor in the area) for to speak about your concerns.

Do I have to participate in this study?

It is your choice whether you want to participate in this study or not. If you decide not to participate, you will not be prejudiced in any way, and your decision will not affect your position at the clinic you work at. If you decide to take part, you are still free to withdraw from the study at any time and without giving a reason. Should you decide not to take part, or if you withdraw from the study, this will in no way affect your position at the clinic. Should you agree to participate, we will ask you to sign the attached consent form.

This study has been ethically reviewed and approved by the UKZN Biomedical research Ethics Committee (approval number_____).

In the event of any problems or concerns/questions you may contact the head researcher, Inge Petersen on 031 260 7970 or the UKZN Biomedical Research Ethics Committee, contact details as follows:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**Research Office, Westville Campus****Govan Mbeki Building**

Private Bag X 54001

Durban

4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604769 - Fax: 27 31 2604609

Email: BREC@ukzn.ac.za

Consent Form for Service Providers

Participation in the study to evaluate the PRIME-SA mental health care programme

Please complete this form after you have been through the information sheet and understand what your participation in this study entails.

Thank you for considering taking part in this study. If you have any questions arising from the information sheet, please ask before you decide whether to take part. You will be given a copy of the information sheet and consent form.

I, (write your name here), _____ have been informed about the study to evaluate the PRIME-SA mental health care programme conducted by Professor Inge Petersen and One Selohilwe.

I understand the purpose and procedures of the study.

I have been given an opportunity to ask questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting my position at the facility I work at.

I have been informed about any available compensation or medical treatment if injury occurs to me as a result of study-related procedures.

If I have any further questions or concerns or queries related to the study, I understand that I may contact the researcher at 031 260 7970 or peterseni@ukzn.ac.za.

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001

Durban

4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604769 - Fax: 27 31 2604609

Email: BREC@ukzn.ac.za

Please tick
or initial

I understand that if I decide at any time during the study that I no longer want to take part, I can notify the researchers and withdraw without having to give a reason.

I consent to the processing of my personal information for the purposes explained to me.

I agree to my interview being audio recorded.

I agree that the research team may use my data (information) for future research and understand that any such use of identifiable data would be reviewed and approved by a research ethics committee. In such cases, as with this project, data would not be identifiable in any report.

Signature of Participant

Date

Signature of Witness
(Where applicable)

Date

Signature of Translator
(Where applicable)

Date

**Participants Informed Consent Form for intersectoral collaboration investigation
(Paper 4) – as part of EMERALD study**



KCL REC reference number: PNM-1314-4

UKZN REC reference number: BE407/13

INFORMATION & CONSENT SHEET FOR PARTICIPANTS

EMERALD: Optimal institutional, legal and policy contexts and system level processes for the implementation of integration policy and service integration plans

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

We would like to invite you to participate in this original research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way.

Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What are we trying to learn from this study?

We are requesting you to participate in a study to identify factors for the optimal implementation of integration policy and service integration plans in low- and middle-income countries (LAMIC). We want to understand factors in the institutional, legal and policy contexts as well as health system processes that either facilitate or act as barriers to the implementation of integration policy and mental health service integration in primary health care in LAMIC. We hope that the findings of this study will help to improve mental health services in LAMIC, and in your region in particular.

Who will be involved in the study and how long will it last?

We are recruiting key stakeholders involved in policy development as well as managers involved in policy implementation for this study. The interviews will run over a period of two months, from March to April 2014.

What will happen if you agree to take part?

If you agree to participate in this study, you will be asked to answer a number of questions about factors that facilitate or hinder the implementation of mental health service integration, from national through to district level. The interviews will take up to one hour. If you agree, your interview will be audio recorded. After the interview, the audio recordings will be transcribed and analysed, after which the recordings from your interview will be deleted.

Are there any risks or disadvantages associated with taking part in the study?

For this study, you will be asked to give one hour of your time, during which you will be interviewed. There are no known disadvantages or risks to you from participating in this study.

Are there any benefits of taking part in the study?

There are no direct benefits to you by taking part in the study. You will not be remunerated for your time. However, this study will help us identify interventions to promote optimal institutional, legal and policy contexts as well as health system processes for the implementation of integration policy and service integration plans in LAMIC, which will help improve mental health services in LAMIC and in your district in particular.

What will we do with your information?

If you consent to your interview being audio-recorded, we will make sure that the audio recordings do not include your name or any information from which you can be identified. If notes are taken instead of audio-recording, these notes will also not include your name or information from which you can be identified. The audio-recordings and notes will be kept in a locked cupboard. Once the interview audio-recordings have been transcribed and the data has been analysed, the recordings will be cleared.

Nobody except the project co-ordinators and project data managers will know that the information belongs to you. We will keep the questionnaires in a locked cupboard and your electronic data will be stored on a computer under password protection. We will take every reasonable step to keep your information and identity confidential.

After the end of this study, the information you give us may be stored and used by other researchers, but they will not be able to identify you in any way.

If we come across any harmful activity during the research, we do not have a legal obligation to tell anyone about this. However, if we think that you or anybody else is at risk of being harmed, we may ask a support team to do something about this, or we can try to help you contact a relevant support person if you wish.

What will we do with the results of the study?

We plan to publish the findings in scholarly journals and at conferences. We will also tell our findings to policy makers within the Ministry of Health in South Africa and other similar countries. No identifying information will be included in these reports and publications; only aggregate data will be reported.

Do I have to take part in the study?

It is up to you to decide whether to take part or not. If you decide not to participate, this will in no way prejudice you. If you decide to take part but later change your mind, you are still free to withdraw from the study at any time and without giving a reason and without prejudice.

You may also withdraw any information you have already provided up until three months after your interview, i.e. by July 2014. A decision to withdraw at any time, or a decision to take part, will not disadvantage you in any way.

If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form.

Who is funding the study?

This study is part of the EMERALD project, which is being funded by the European Union's 7th Framework Programme.

Who is carrying out the study?

The study is part of the EMERALD (Emerging mental health systems in low- and middle-income countries) project, which is being carried out in Ethiopia, India, Nepal, Nigeria, South Africa and Uganda. The project is led by Professor Graham Thornicroft from the Institute of Psychiatry, King's College London. The study in South Africa is being carried out under Professor Inge Petersen at the University of KwaZulu-Natal. The project manager is Debbie Marais, who is also based at the University of KwaZulu-Natal and will be coordinating these interviews. The people conducting these interviews are Debbie Marais, Tasneem Kathree, Carrie Brooke-Sumner and One Selohilwe.

If you have any questions or require more information about this study, please contact the research team using the following contact details:

Prof Inge Petersen

Psychology, School of Applied Human Sciences, University of KwaZulu-Natal

Tel: 031 260 7970

Email: peterseni@ukzn.ac.za

Debbie Marais

Tel: 033 260 5770

Email: maraisd@ukzn.ac.za

If this study has harmed you in any way, you can contact the Biomedical Research Ethics Committee (BREC) at the University of KwaZulu-Natal, using the details below for further advice and information:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604769 - Fax: 27 31 2604609

Email: BREC@ukzn.ac.za

CONSENT FORM FOR PARTICIPANTS IN RESEARCH STUDIES



Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study:

EMERALD: Optimal institutional, legal and policy contexts/system level processes for the implementation of integration policy and service integration plans

King's College Research Ethics Committee Ref: PNM-1314-4

Local Research Ethics Committee Ref: BE407/13

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Please tick or initial

- I understand that if I decide at any time during the research that I no longer wish to participate in this project, I can notify the researchers involved and withdraw from it immediately without giving any reason. Furthermore, I understand that I will be able to withdraw my data up until July 2014.
- I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the local data protection rules and the rules of the UK Data Protection Act 1998.
- I understand that the information I have submitted will be published as a report. I have noted that confidentiality and anonymity will be maintained and it will not be possible to identify me directly from any publications.

- I agree that the research team may use my data for future research and understand that any such use of identifiable data would be reviewed and approved by a research ethics committee. (In such cases, as with this project, data would not be identifiable in any report).

- I agree that my data will be archived in anonymised form, so that other researchers may use my data for future research. I understand that any such use of identifiable data would be reviewed and approved by a research ethics committee. (In such cases, as with this project, data would not be identifiable in any report).

- I agree for my interview to be audio-recorded.

Participant's Statement:

I _____

agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signed

Date

Witness Statement (in event that participant is not literate):

I _____

agree that the research project named above has been explained to

_____ (participant) to his/her satisfaction and that s/he agrees to take part in the study. Both the notes written above and the Information Sheet about the project have been read to him/her, and s/he understands what the research study involves.

Signed

Date

Investigator's Statement:

I _____

confirm that I have carefully explained the nature, demands and any foreseeable risks (where applicable) of the proposed research to the participant.

Signed

Date

Appendix 4 Interview Schedules

Interview guide for interviews with Mental Health Care Users (Paper 1)

Objective of Questionnaire

To establish among mental health care users their subjective understanding of their mental disorder (generally psychosis, but could include bi-polar disorder or severe depression), what they think are the potential influences of their disorder, and how they think they can be helped with this mental health problem.

Research Questions

- 1) How do mental health care users understand the phenomenon of psychosis, particularly in terms of its manifestations and course and effects on social roles and functioning?
- 2) What influences do mental health care users identify as a source of their mental illness?
- 3) What are existing pathways to care and how can these be improved to promote greater identification, access and demand?
- 4) What interventions do they perceive as helpful for rehabilitation and integration with their community?
- 5) How would these interventions meet the needs of mental health care users?
- 6) How can demand for mental health care services be increased?
- 7) What are attitudes to task shifting?
- 8) How to increase accountability of service providers?
- 9) How to reduce stigma and discrimination?
- 10) What does recovery mean and what supports recovery from severe mental illness in this context?

Guidelines

Welcome and introduction

Greeting

Thank participants for agreeing to participate

Explaining the project (including what is meant by common mental health problems)

Explaining the rationale for the interview

INTRODUCTION

At present in South Africa, many people who suffer from mental disorders can't get treatment because there aren't enough specialists to deliver the care. In this study we are working with South Africa's Ministry of Health to try to improve this situation. In order to ensure that the service developed understands your context and fits with local understandings of mental illness and healing, we are interested to hear about your opinions on how people with mental illness can best be helped. Thank you for agreeing to participate and giving your time.

Abbreviations used:

CHW: Community Health Worker

PHC: Primary Health Care

Interview questions

Cultural / General understanding/Causes of severe mental illness

1. How would you know if a person has a mental illness (psychosis, bi-polar disorder, severe depression)? (Probe for understanding of mental illness e.g., is it understood as witchcraft, stress, nerves etc.)
2. Do you see yourself as having this problem (severe mental illness)? Explain why or why not, including if others have told him/her that s/he has a mental illness (If yes, please explain how this {mental illness} feels for you?). (Probe for signs and symptoms).
3. How do these symptoms affect your life? (Probe for the problems they have caused for the participant).
4. How long do you think this illness will last?
5. What do you think caused these feelings?

Prompt:

- Incidences and situations (e.g. stress, etc.)
- Cultural interpretations e.g. witchcraft

6. Can you describe days when you feel worse?

Prompt:

- What makes it worse?

- Are there particular situations?
- Is there something you did yourself?
- Is there something someone else did? What did they do?

7. Do you take your psychotropic medicines regularly?

If No: What affects your ability to take your psychotropic medicines regularly?

Prompt:

- What makes it difficult?
- Can you remember situations when you didn't take your medication?

Pathways to Care (including identification and demand)

8. What made you seek help for your illness?

Prompt:

- Did you identify yourself as having a mental illness?
- Did someone else identify your problem of mental illness and suggest you seek help? **If yes**, who was this person and who did they suggest you seek help from?
- Who did you seek help from?
- How did you know where to seek help from?
- What was the nature of the help you received?
- What was your experience of the help you received?
- How long did it take to get help once identified as having a mental illness?
- Would you seek help from this source again for your illness?
 - **If yes** – Why?

- **If no** – Why not?

9. Did you feel better after seeking this help?

10. Are you aware of any services besides medication to help you with your illness (e.g. counselling or a support group for people with severe mental illness)?

- **If yes**, have you or someone you know who has a severe mental illness ever sought additional help for this problem besides medication (e.g. attended a support group for people with severe mental illness)?

- What made you seek help?
- Who did you seek help from?
- How did you know where to seek help from?
- What was the nature of the help that you received?
- Would you seek help from this source again for your illness?

- **If yes**- why?
- **If no**-why not?

11. Are you aware of any services specifically offered by Government (including Department of Health) besides medication to help you with your mental illness?

- **If No**, do you think that if such services were available people like yourself would want to use them?

Prompt:

- What could be done to improve identification of people like yourself with mental illness in the community?
- What can be done to make mental health services easier to access for the poorest people in the community?
- What would help to make people want to use these services?

- Would increasing awareness of the causes, symptoms and how people can be helped with mental illness improve demand?
- Would bringing the service closer to where people live help improve demand?
- Would ensuring that the service fits with local understandings of mental illness and treatment help improve demand?
- What would motivate you to join and remain part of a support group?

If yes, what services are you aware of?

- Were you able to access these services with ease?
- If you were not able to access them with ease,
 - Is distance or transport an issue?
 - Is cost of services an issue?
 - Is finding someone to go with you an issue?
 - Is there a lack of understanding of local views of mental health issues?
 - Is there a concern about quality of care in PHC?
 - Is there a concern about availability of medicines?
 - Is there a concern about the availability and quality of counselling?
 - Can you think of anything else that could be done to make it easier to access these services?

What interventions are perceived as helpful? (treatment and pathways through care and how can these be improved)

12. Can you describe days when you feel better.

Prompt:

- What makes it better?
- Was there anything you did yourself?
- Was there someone who assisted you to feel better? If so, whom? What did they do?

13. What helps you to take your medication regularly?

Prompt:

- What makes it easy?
- What makes it difficult?

14. If you could imagine the perfect way to help people like yourself who are troubled by mental illness in this community, what would it be like?

Prompt:

- What do you think can be done?
- Would it be best done alone or with other people? (What are the reasons for your choice?)
 - Where would it take place?
 - Who would provide this help?

- What could the community do to help?
- What could be done by PHC nurses?
- What could be done by CHWs?
- What do you think some of the benefits of this help might be?
- What do you think some of the difficulties / obstacles to getting this help might be?

Attitudes to Task-Shifting

15. If general health workers, such as nurses and CHWs were trained to provide treatment such as medication or counselling for mental illness, would this be acceptable to yourself and others in your community?

Prompt:

- Would treatment services for mental illness provided by nurses be acceptable?
 - **If Yes**, what kind of services would be acceptable for them to provide?
 - **If No**, probe for why not.
- Would treatment services for mental illness provided by CHWs be acceptable?
 - **If yes**, what kind of services would be acceptable for them to provide?
 - **If No**, probe for why not.

Accountability

16. Is there some way in which people can indicate whether they are satisfied with mental health care services?
- **If yes**, what methods currently exist?
 - **If no**, what method can you think of that could be put in place that would help with this?

Stigma and Discrimination

17. As someone with mental illness, have you experienced negative attitudes from service providers such as being disrespected, ignored or discriminated against?
- **If yes**, can you describe this experience – what happened?
 - What could be done to change this?
18. How do you feel when you wait at the clinic or health facility to get your treatment?
- Do people recognize you as someone who has a mental illness?
 - Do you feel stigmatized by other people at the clinic/health facility who are there for other reasons?
 - Would you prefer to have a separate queue/waiting area dedicated just for people with mental illness or do you prefer to wait together with other service users? Why?
 - Would you prefer to see a nurse who deals with your type of illness specifically or a nurse who sees all problems?
19. As someone with mental illness, have you experienced negative attitudes from people in your community and/or at your work place such as being disrespected, ignored or discriminated against?
- **If yes**, can you describe this experience – what happened?
 - What could be done to change this?

- Do you think awareness-raising of severe mental illness in relation to the causes, symptoms and how people can help, will be helpful for reducing stigma and discrimination?
- How do community members treat you?

FUNCTIONING & RECOVERY

20. How does your illness affect your ability to function?

Prompt:

- Independence- how does it affect your ability:
 - To manage money?
 - To use public transport?
 - To look after family/children?
 - To set goals for your future?

21. Do you feel that you have lost confidence in yourself since you have suffered from this illness?

Prompt:

- What would it take for you to regain your self-confidence?
- What would make you feel like you are more in control of your life?
- What would give your life more meaning and purpose?

22. What social activities or groups do you miss out on since you have had this illness?

Prompt:

- What would you like to be involved in?
- What could be done to help you be more involved socially?

23. What factors in your community make it difficult for you to function?

Prompt:

- Are you excluded from community activities or opportunities?
- What could be done to change this?

24. Do you believe that it is possible to recover from mental illness?

- What would recovery mean for you? Probe
- Does recovery mean being able to work and contribute in your family?
- What else would recovery mean for you?
- What personal growth and development would you like to pursue? Probe: (e.g. goals, dreams)
- What gives you hope that this is possible?

25. If you are not working now, what type of work did you do in the past?

Prompt :

- With medication and symptom management could you go back to the job?
- What is the attitude of employers to people with mental illness? Would this stop them from giving you a job?
- How would your symptoms affect your ability to do this job?
- How does your illness affect your relationships with people you work with?
- Have there been work or other opportunities you have missed out on because of your illness? What are they?

26. How do family members treat you?

Prompt:

- Do you feel your family understand your illness?
- Are there times when you feel you are not a valued member of your family?
 - What makes this worse?
 - What makes this better?

27. Do you get any government grants to help support you and financially?

If Yes:

- How do you access it?
- Who controls this money? Probe for problems with family abusing grants.
- Do you or your family control how the money from the grant is spent?
- Have you ever got into debt by buying things on credit against the money you will get from your grant?
- What does the grant cover for you/your family?
- Who is dependent on the grant?
- Although you have a grant to help support you, would you want to be part of a self-help group where you could get other types of support?

Prompt:

- Why or why not?

28. Have you ever used the money from your grant to start any type of income-generating activity?

If Yes:

- What did you do?
- How did you use the money?
- Did you work individually or as part of a group?
- How did this help you?
- What did you learn from this activity? Would you do it again?

If No:

- How could you use some of your grant money to do something to generate an income?
- Would you prefer to work on your own or as part of a group?
- What training or support would you need to be able to do this? (e.g. financial management training or training on a particular skill)

29. Have you ever experienced stigma because you get a grant?

- What did you experience?
- Why do you think this happened?
- What do you think could be done to change this?

30. If you could be involved in a project working with other people suffering from mental illness what type of work would you like to do?

Prompt:

- What do you feel confident that you could do?
- What would you enjoy?
- What do you think is needed in your community?
- What would help others in your family/community to see those with mental illness as valuable members of the community?

31. Are there any existing projects/self help groups in your community that you would like to be part of?

Prompt:

- Do you think people in this group would accept and support you?
- Would you prefer to:
 - a) Join a group with general members of your community
 - or
 - b) Be part of a group of people who also have a mental illness like yours?

32. Would you be willing to be trained for a specific skill if this training was available to you?

Prompt:

- What type of training would you be interested in?
- What type of work would you least like to do?
- What type of work would you most like to do?
- What strengths do you have that you could build on?

33. Would you be interested in volunteering your time and your skills to serve your community?

- In what ways could you be involved in serving your community?

34. What are the most important things that prevent you from having good quality of life?

Prompt:

- How has your life changed since your illness?

35. Do you think there may be any issues that we may have not adequately covered in this interview?

Interview guide for interviews with Caregivers of Mental Health Care Users (Paper 1)

Objective of Questionnaire: To establish among caregivers of mental health care users their subjective understanding of the mental disorder (generally psychosis, but could include bi-polar disorder or severe depression), and how they think people can be helped with this mental health problem.

Research Questions

- 11) How do caregivers of mental health care users understand the phenomenon of psychosis, particularly in terms of its manifestations and course?
- 12) What influences do caregivers of mental health care users identify as a source of their mental illness?
- 13) What interventions do they perceive as helpful?
- 14) How would these interventions meet the needs of mental health care users?
- 15) What are existing pathways to care and how can these be improved to promote greater identification, access and demand?
- 16) What are attitudes to task shifting, including provision of psychosocial support by auxiliary social workers?
- 17) How do caregivers believe accountability can be increased?
- 18) How do caregivers think stigma and discrimination can be reduced?
- 19) Do caregivers see recovery as a possibility for the person they care for?

20) What roles and activities would be linked to their recovery?

21) What factors in the community would be needed for recovery?

22) Would caregivers be motivated to be involved in a self-help group intervention along with the family members they care for?

Guidelines

Welcome and introduction

Greeting

Thank participants for agreeing to participate

Explaining the project (including what is meant by common mental health problems)

Explaining the rationale for the interview

INTRODUCTION

At the present time in South Africa, many people who suffer from mental disorders can't get treatment because there aren't enough specialists to deliver the care. In this study we are working with South Africa's Ministry of Health to try to improve this situation. In order to ensure that the service developed is contextually appropriate and resonates with local understandings of mental illness and healing, we are, therefore, interested to hear about your opinions on how people with mental illness can best be helped. Thank you for agreeing to participate and giving your time.

Interview questions

Cultural / General understanding/Causes of severe mental illness

1. How would you know if a person has a mental illness (psychosis, bi-polar disorder, severe depression)? (Probe for understanding of mental illness e.g., is it understood as witchcraft, stress, nerves etc.)

2. Do you see your family member (the person you care for) as having this problem (severe mental illness)? Explain why or why not (If yes, please explain how this {mental illness} manifests for them and how you view this illness). Probe for signs and symptoms.

3. How do these symptoms affect their life?
 - Probe for the problems they have caused for the person they care for.
 - Probe for limitations in roles and activities that the person has experienced due to their illness.

4. How long do you think it will last?

5. What do you think caused these feelings?

Prompt:

 - Incidences and situations (e.g. stress, etc.)
 - Cultural interpretations (e.g. witchcraft)

6. Can you describe days when they feel worse or when their symptoms seem worse to you?

Prompt:

- What makes it worse?
- Was there a particular situation?
- Was there something the person did to make it worse?
- Was there something someone else did? What did they do?
- How do you feel when things are worse?
- What do you do when things are worse?

7. How has their illness affected **YOUR** life?

Prompt:

- What activities are you unable to do (e.g. going to work, household chores)
- How do you feel? Do you experience stress?
- Do people in your family/community treat you differently?

8. What affects the ability of the person you care for to take their psychotropic medicines regularly?

Prompt:

- What makes it difficult?
- Can you remember situations when they didn't take their medication?

9. Has the person you care for had to go back to hospital on more than one occasion due to their illness?

Prompt:

- Why do you think this happens?
- What have you done in these situations?

What interventions are perceived as helpful?

10. What helps the person you care for to take their medication regularly?

Prompt:

- What makes it easy?

11. Can you describe days when they feel better.

Prompt:

- What makes it better?
- Was there anything the person did to feel better?
- Was there someone who assisted the person to feel better? If so, whom? What did they do?
- Are there particular ways in which you help the person to feel better?
- If yes, what are they?

12. How do **YOU** feel on the days when they are better?

Prompt:

- What are you able to do that you can't usually do?

13. How do you feel on the days when they are worse?

14. How do you cope with your family member's illness in your day to day life?

Prompt:

- What are your own personal coping strategies? (e.g. for dealing with stress).

15. If you could imagine the perfect way to help people like your family member who are troubled by mental illness in this community, what would it be like?

Prompt:

- What do you think can be done?
- Would it be best done alone or with other people? (what are the reasons for your choice?)
 - Where would it take place?
 - Who would provide this help?
 - What could be done by social workers?
 - Would you want to be involved?

16. What do you think some of the benefits of this type of help might be for your family member?

17. What do you think some of the benefits of this help might be for you, and other people in your family?

18. What do you think some of the difficulties / obstacles to getting this help might be?

19. Do you think your community is supportive of people with mental illness like your family member?

Prompt:

- What could be done to make your community more supportive?
- How would this affect you and the person you care for?

Pathways to Care (including identification and demand)

20. What made your family member seek help for their illness?
- Did the person recognise herself / himself that he/she has a mental illness?
 - Did someone else identify the problem of mental illness and suggest that the person seek help?
 - If yes, who was this person and who did they suggest you/your family member seek help from?
 - How did you/your family member know where to seek help from?
 - What was the nature of the help your family member received?
 - What was your family member's experience of the help she/he received?
 - How long did it take to get help once identified as having a mental illness?
 - Would you/your family member seek help from this source again for their mental illness?
 - If yes – Why?
 - If no – Why not?
21. Are you aware of any services besides medication to help your family member with their illness (e.g. a support group for people with severe mental illness)?
- If yes, have you, your family member or someone you know who has a severe mental illness ever sought additional help (e.g. attended a support group)?
 - If no-why not?

22. What would motivate the person you care for to join and remain part of a self help group/support group if it existed?

23. What would motivate you to join a self help group/support group that also involved caregivers?

Prompt:

- What do you think the benefits of this type of group could be for you and for the person you care for?

24. Are you aware of any services specifically offered by the Department of Health or Department of Social Development to help your family member with their mental illness?

- If no, do you think that if such services were available people like yourself/your family member would want to use them?
- What could be done to improve identification of people like your family member with mental illness in the community?
- What can be done to make mental health services easier to access for women in the community?
- What can be done to make mental health services easier to access for the poorest people in the community?
- What would help to make people want to use these services?
 - Would increasing awareness that you can be helped improve demand?
 - Would making the service closer to where people live help improve demand?
 - Would ensuring that the service fits with local understandings of mental illness and healing help improve demand?

- If yes, were you/your family member able to access these services with ease?
- If you were not able to access them with ease,
 - Is distance or transport an issue?
 - Is cost an issue?
 - Is finding someone to go with your family member an issue?
 - Is taking time off from work to accompany your family member an issue?
 - Is there a problem with a lack of understanding of local understandings of mental illness and healing?
 - Is there a concern about quality of care in PHC / availability of medications?
 - Can you think of anything else that could be done to make it easier to access these services?

Disability Grants

25. Does your family member get a government disability grant?

Prompt:

- How do they access the grant?
- Who controls how the money from the grant is spent?
- What does the grant cover?
- Who is dependent on the grant?
- Have you or your family member ever got into debt by buying things on credit against the money you will get from the grant?

26. Although your family member has a grant to help support them, do you think they would want to be part of a self-help group where they could get other types of support (e.g. emotional support)?

- Why or why not?

27. Do you think that getting a grant encourages your family member to remain 'ill'?

Probe:

- Does your family member ever stop taking their medication to ensure that they are still eligible for their grant?

Attitudes to Task-Shifting

28. If auxiliary social workers were trained to provide psychosocial interventions such as counselling or support groups for mental illness, would this be acceptable to people such as your family member who has a mental disorder, and yourself?

- If yes, what kind of interventions would be acceptable for them to provide?
- If no, probe for why not.

Accountability

29. Is there some way in which people can indicate whether they are satisfied with mental health care services?

- If yes, what methods currently exist?
- If no, what method can you think of that could be put in place that would help with this?

Stigma and Discrimination

30. As someone with mental illness, has your family member experienced negative attitudes from other people such as being ignored or excluded from activities or unfairly discriminated against e.g., in the workplace?

- If yes, can you describe this experience – what happened?
- What could be done to change this?
- Do you think awareness-raising can be helpful?

31. Have you yourself experienced stigma or discrimination because you care for a family member with a mental illness?

- If yes, can you describe this experience – what happened?
- What could be done to change this?

32. How do other family members treat you and the person you care for?

Prompt:

- Do you feel your family understand the illness?

Recovery from Mental Illness

33. How does your family member's illness affect their ability to function?

Prompt:

- Interpersonally, how does it affect their relations with family?
- How does it affect their relations with community members?
- How does it affect their ability to work / generate an income?
- Independence- how does it affect their ability:
 - To manage money?
 - To use public transport?

34. Do you believe that it is possible for the person you care for to recover from their mental illness?

- What do you think recovery would mean for them?
- What would their recovery mean for you?

35. Do you think that the person you care for has lost confidence in him/herself since suffering from mental illness?

- What would it take for them to regain their self confidence?
- What would make them feel like they are more in control of their lives?
- What are the things they value doing that would help them regain confidence?

36. What social activities or groups does the person you care for miss out on since they have had this illness?

- Have their social skills been affected?
- What could be changed to help them be more involved socially?
- Do people accept them socially?

37. Did the person you care for have roles or activities in your family or community that were important for them that they are no longer able to fulfil?

Prompt:

- Have their roles as a parent or husband/wife been affected?
- Did they have a role in your community (e.g. part of a local council or community group) that they are no longer able to fulfil?

38. Apart from their illness what things prevent the person you care for from being able to do the things that are important to them?

Prompt:

- Do people refuse to accept them in social/community activities?
- Do they have constraints in their living circumstances? (e.g. lack of transport)

39. What factors in your community make it difficult for the person you care for to function?

Prompt:

- Are they excluded from community activities or opportunities?
- What could be done to change this?

40. Do you think there may be any issues that we may have not adequately covered in this interview?

Baseline Interview guide for pilot programme - psychosocial rehabilitation for Schizophrenia Service Users (Paper 3)

Objective

This interview aims to understand the perspectives of service users with schizophrenia on their illness and experiences on joining the psychosocial rehabilitation support group. The findings from these interviews will be used for a process evaluation of the programme.

Research Questions

1. What are service users experiences and perceptions on their illness, functioning and social inclusion?
2. What are service users' understandings of causes and course of their illness?
3. What is service users' knowledge on illness and medication?

Guidelines

Welcome and introduction

Greeting

Thank participants for agreeing to participate

Explain the project

Explain the rationale for the interview

INTRODUCTION

At present in South Africa, many people who suffer from mental disorders can't get the support they need because there aren't enough specialists to deliver the care. In this study we are working with South Africa's Ministry of Health to try to improve this situation. In order to ensure that the support groups for psychosocial rehabilitation meet your needs and work effectively, we are interested to hear about your opinions and experiences. Thank you for agreeing to participate and giving your time.

Interview questions

Symptoms, Illness and Medication Knowledge

1. What do you understand your diagnosis to be?

Probe: Do you know what schizophrenia is?

2. What symptoms do you have?

3. How do these symptoms affect your life? (Probe for the problems they have caused for the participant).

4. What do you think caused your mental illness?

Prompt:

Incidences and situations (e.g. stress, etc.)

Cultural interpretations e.g. witchcraft

5. How long do you think this illness will last?

6. Do you believe that it is possible to recover from your mental illness?

- Probe: Does recovery mean being able to work and contribute in your family?
- What else would recovery mean to you?

7. What medication do you take for your illness?

- Probe: Name? Tablet/injection?

8. What directions do you have from the doctor on how to take your medication?

- Probe: Do you follow these?

9. What side effects does your medication have?

Probe: Do you know how to deal with these?

Functioning and Social Inclusion

10. How does your illness affect your ability to function?

Prompt:

- Independence- how does it affect your ability:
 - To manage money?
 - To use public transport?
 - To look after family/children?
 - To set goals for your future?

11. Are there any roles in your family or community that you are not able to carry out because of your illness?

Prompt:

- Roles in family e.g. childcare
- Roles in community e.g. community leader
- Roles at Work
- Roles in the Household e.g. cooking, cleaning
- Roles in church or other community organisation

12. What are the most important things that prevent you from having good quality of life?

Prompt:

- How has your life changed since your illness?

13. Do you get any government grants to help support you financially?

If Yes:

- Who controls this money?
 - Do you or your family control how the money from the grant is spent?
 - Who is dependent on the grant?

14. Have you had a relapse which has made it necessary for you to go into hospital in the past 12 months?

- If yes – how many relapses? What do you believe caused the relapses?
- If no – when was the last time you were in hospital, if ever? What has prevented you from needing to be hospitalised?

15. Have you had problems with alcohol and substance abuse in the past 12 months?

16. Have you had an encounter with law enforcement in the last 12 months?

- If yes – please explain the situation and what happened.
- If this has happened more than once, how many times has it happened?

17. How do family members treat you?

Prompt:

- Do you feel your family understand your illness?
- Are they supportive?

18. Are there any issues we have not adequately covered in this interview?

Midpoint Interview guide for pilot programme - psychosocial rehabilitation for Schizophrenia Service Users (Paper 3)

Objective

This interview aims to understand the perspectives of service users with schizophrenia on their illness and experiences on joining the psychosocial rehabilitation support group, and on monthly intervals for the next two months. The findings from these interviews will be used for a process evaluation of the programme.

Research Questions

- 1.** Does the intervention show potential for reducing symptoms and improving functioning in this context?
- 2.** What are service users' perceptions on the appropriateness of intervention content?
- 3.** What are service users' perceptions on acceptability of the intervention?

Guidelines

Welcome and introduction

Greeting

Thank participants for agreeing to participate

Explain the project

Explain the rationale for the interview

INTRODUCTION

At present in South Africa, many people who suffer from mental disorders can't get the support they need because there aren't enough specialists to deliver the care. In this study we are working with South Africa's Ministry of Health to try to improve this situation. In order to ensure that the support groups for psychosocial rehabilitation meet your needs and work effectively, we are interested to hear about your opinions and experiences. Thank you for agreeing to participate and giving your time.

Interview questions

Symptoms, Functioning and Social Inclusion

1. Have you noticed any changes in your symptoms since you have been involved in the support group?

Probe:

- Are there any changes that you feel are due to being involved in the support group particularly?

2. Have you have seen any changes in your ability to function since being part of this group?

Prompt:

- Are there tasks that you now find easier?

3. Are there any roles in your family or community that you now able to carry out that you could not before?

Prompt:

- Roles in family e.g. childcare
- Roles in community e.g. community leader
- Roles at Work
- Roles in the Household e.g. cooking, cleaning

- Roles in church or other community organisation
4. Have you had a relapse which has made it necessary for you to go into hospital since being in the support group?
 - If yes – how many relapses? What do you believe caused the relapses?
 - If no – when was the last time you were in hospital, if ever? What has prevented you from needing to be hospitalised?
 5. Have you had problems with alcohol and substance abuse since being in the group?
 6. Have you had an encounter with law enforcement since being part of the group?
 - If yes – please explain the situation and what happened.
 - If this has happened more than once, how many times has it happened?
 7. Do you think your being part of this group has helped people in your family and community understand you and your illness?

Prompt:

 - Why or Why not?
 - Has this changed the way they treat you? If so, how?

Implementation of programme

8. Can you describe what your group usually did when you met?

Prompt:

 - Education on illness and treatment?
 - Income generating activities?

9. Can you describe the role of the facilitator in the group?

Prompt:

- What information did they provide?
- What support did they give?

10. What motivated people to join the group?

Probe:

- What motivated people to keep coming to group meetings?
- What discouraged people from coming to group meetings?

11. Has your group stayed active over the past weeks?

Appropriateness of intervention type and content

12. A support group is one way of supporting people with schizophrenia, do you think it is a good way?

If yes:

- What benefits have you seen for yourself and others in the group?
- What do you enjoy about the group?

If no:

- What other way do you think would be better to support people with schizophrenia, and why?

13. Has the information given to you by the facilitator been helpful?

If yes:

- What has been the most useful information and why?
- What additional information would have been helpful?

If no:

- What information would you have liked for the facilitator to give?

14. Was information presented to you in a way that was easy to understand and apply to your life?

Probe:

- Can you give an example of something you learned in the group and then applied to your life?

15. Which session did you enjoy the most?

Probe:

- Why?

16. Which session was the most useful?

Probe:

- Why?

17. Which session did you enjoy the least?

Probe:

- Why?

Perceptions of quality of training of service providers

18. Do you feel that the facilitators of your group had all the training they needed to be able to support you?

- If yes – what makes you feel that the facilitators were well trained?
- If no – why not?

19. Did the facilitator seem confident and organized?

Probe: Why or Why not?

20. Did the facilitator refer you to another service provider for help/support if you needed it?

If yes: Please can you describe where you were referred and why.

Acceptability of Intervention

21. Is this support group something that you would like to continue to be involved in?

22. Do you feel comfortable being involved in the group?

Why/Why not?

23. Are you able to get to the group meetings easily?

24. Are the group meetings held in an appropriate and easily accessible venue?

25. Has the group gained acceptance in your community?

- If yes: Please describe why you think this has happened.
- If no: Please describe why you think this has not happened.

Adaptations/improvements for intervention

26. What, if anything, would you like to change about the support group?

Prompt:

- What would you change about how the group is run?
- What would you change about the activities you do?
- What would you change about who is involved in the group?
- Would you change the venue where the group meets?

27. Are there are any issues we have not adequately covered in this interview?

Endpoint Interview guide for pilot programme - psychosocial rehabilitation for Schizophrenia Service Users (Paper 3)

Objective of Questionnaire

This interview aims to understand the perspectives of service users with schizophrenia on their experience of the support group programme after the implementation of the pilot.

Research Questions

1. Does the intervention lead service users to express that they have had improved symptoms and functioning?
2. Does the intervention improve social inclusion for service users in their community?
1. What are service users opinions overall of the acceptability and content of the programme?

Guidelines

Welcome and introduction

Greeting

Thank participants for agreeing to participate

Explain the project

Explain the rationale for the interview

INTRODUCTION

At present in South Africa, many people who suffer from mental disorders can't get the support they need because there aren't enough specialists to deliver the care. In this study we are working with South Africa's Ministry of Health to try to improve this situation. In order to ensure that the support groups for psychosocial rehabilitation

meet your needs and work effectively, we are interested to hear about your opinions and experiences. Thank you for agreeing to participate and giving your time.

Interview questions

Symptoms, Illness and Medication Knowledge

1. What do you understand your diagnosis to be?

2. What symptoms do you have?

3. How do these symptoms affect your life?

Probe for the problems they have caused for the participant).

4. What do you think caused your mental illness?

5. What medication do you take for your illness?

Probe: Name? Tablet/injection?

6. What directions do you have from the doctor on how to take your medication?

Probe: Do you follow these?

7. What side effects does your medication have?

Probe: Do you know how to deal with these?

8. Have you been taking your medication for your illness regularly over the past 3 months?

- If yes – what helps you to take your treatment regularly? Have you noticed a difference since being part of the support group?
- If no – What prevents you from taking your treatment? What would help you take your treatment regularly in the future?

9. Have you had a relapse of your illness which has made it necessary for you to go into hospital in the past 3 months?
- If yes – how many relapses? What do you believe caused the relapses?
 - If no – when was the last time you were in hospital, if ever? What has prevented you from needing to be hospitalised?

Functioning and Social Inclusion

10. Have you have seen any changes in your ability to function since being part of this group?

Prompt:

- Are there tasks that you now find easier?

11. Are there any roles or functions in your family or community that you have taken up since being part of the support group?

Prompt:

- Roles in family e.g. childcare
- Roles in community e.g. community leader
- Roles at Work
- Roles in the Household e.g. cooking, cleaning
- Roles in church or other community organisation

12. What about this/these role/s is important to you?

- 13.** Have you had problems with alcohol and substance abuse over the past 3 months?
- If yes – do you think it is related to your mental illness? Has being part of the support group discouraged you from abusing alcohol and drugs?
 - If no – what has helped you to avoid using alcohol and drugs? Has being part of the support group helped you in this?
- 14.** Have you had an encounter with law enforcement over the past 3 months?
- If yes – please explain the situation and what happened.
 - If this has happened more than once, how many times has it happened?
- 15.** Have you received your disability grant over the past 3 months?
- If yes – what do you use the grant for? Has this changed since you have been part of the support group?
 - If no – do you know that people with psychiatric disability are eligible for government grants? Do you know where to go to access these grants?
- 16.** Does your caregiver manage your grant money or do you do this yourself? Has this changed since being part of the support group?
- 17.** How do family members treat you?
- Prompt:
- Do you feel your family understand your illness?
 - Are they supportive?
- 18.** Do you think your being part of this group has helped people in your family and community understand you and your illness?
- Prompt:
- Why or Why not?
 - Has this changed the way they treat you? If so, how?

19. Do you feel excluded from social activities that your family or community participate in? Has this changed since being part of the support group?

Prompt:

- What social activities do you now participate in?

20. Have you made new friendships through being part of the support group?

Prompt:

- If yes, How has this affected your life?
- If no, What makes it hard to build friendships?

Skills and Goal Setting

21. Have you gained any skills since being part of the support group?

- If yes, please describe these skills and how they have affected your life.

22. Has the support group has helped you to set goals and work towards these?

Prompt:

- What goals have you set? Have you made progress towards achieving these goals?

Appropriateness of intervention type and content

23. A support group is one way of supporting people with schizophrenia, do you think it is a good way?

If yes:

- What benefits have you seen for yourself and others in the group?
- What do you enjoy about the group?

If no:

- What other way do you think would be better to support people with schizophrenia, and why?

24. Has the information given to you by the facilitator been helpful?

If yes:

- What has been the most useful information and why?
- What additional information would have been helpful?

If no:

- What information would you have liked for the facilitator to give?

25. Was information presented to you in a way that was easy to understand and apply to your life?

Probe:

- Can you give an example of something you learned in the group and then applied to your life?

26. Which session did you enjoy the most?

Probe:

- Why?

27. Which session was the most useful?

Probe:

- Why?

28. Which session did you enjoy the least?

Probe:

- Why?

Perceptions of quality of training of service providers

- 29.** Do you feel that the facilitators of your group had all the training they needed to be able to support you?
- If yes – what makes you feel that the facilitators were well trained?
 - If no – why not?
- 30.** Did the facilitator seem confident and organized?
Probe: Why or Why not?
- 31.** Did the facilitator refer you to another service provider for help/support if you needed it?
- If yes: Please can you describe where you were referred and why.

Acceptability of Intervention

- 32.** Is this support group something that you would like to continue to be involved in?
- 33.** Do you feel comfortable being involved in the group?

Why/Why not?
- 34.** Are you able to get to the group meetings easily?
- 35.** Are the group meetings held in an appropriate and easily accessible venue?
- 36.** Has the group gained acceptance in your community?
- If yes: Please describe why you think this has happened.
 - If no: Please describe why you think this has not happened.

Adaptations/improvements for intervention

37. What, if anything, would you like to change about the support group?

Prompt:

- What would you change about how the group is run?
- What would you change about the activities you do?
- What would you change about who is involved in the group?
- Would you change the venue where the group meets?

38. What is your overall feeling about the support group after being involved for 3 months?

39. Do you think there may be any issues that we may have not adequately covered in this interview?

Interview guide for pilot assessment of intervention for psychosocial rehabilitation with Service Providers (Paper 3)

Objective of Questionnaire

This interview aims to understand the perspectives of service providers (auxiliary social workers and others) for the PRIME intervention for psychosocial rehabilitation, 3 months after initiation of the pilot. The findings from these interviews will be incorporated into a process evaluation of the pilot implementation.

Research Questions

1. What are service providers' perceptions on the effectiveness of their training and the materials provided?
2. What are service providers' perceptions on the acceptability and appropriateness of intervention content?
3. What are service providers' perceptions on what could be changed/improved in the intervention?

Guidelines

Welcome and introduction

Greeting

Thank participants for agreeing to participate

Explain the project

Explain the rationale for the interview

INTRODUCTION

At present in South Africa, many people who suffer from mental disorders can't get the support they need because there aren't enough specialists to deliver the care. In this study we are working with South Africa's Ministry of Health to try to improve this situation. In order to ensure that the intervention for psychosocial rehabilitation developed functions effectively and benefits service users, we are interested to hear about your opinions and experiences after being involved with support group pilot. Thank you for agreeing to participate and giving your time.

Interview questions

Implementation

1. Can you describe what your group usually did when you met?

Prompt:

- Skills training?
- Education on illness and treatment?
- Cooperative/income generating activities?

2. Can you describe your role in the group?

Prompt:

- What information did you provide?
- What support did you give?
- What other role/s did you play?

3. Has your group stayed active over the past 3 months, or have people stopped coming to meetings?

Probe:

- Why do you think they have kept coming/stopped coming?

- What could be done to improve this?
4. Have you noticed any changes in members of your group/s over the past 3 months?

Probe:

- Please describe these.

Acceptability and feasibility of intervention

5. A self help group is one possible way of supporting people with schizophrenia, and their caregivers do you think it is a good way?

If yes:

- What benefits have you seen for people in the group?

If no:

- What other way do you think would be better?

6. Do you think group members benefit from these groups?
7. Do you think group members want to continue to be part of these groups?
8. Are members able to get to the group meetings easily?
9. Are the group meetings held in an appropriate and easily accessible venue?
10. Are there any logistical issues that have made running the groups difficult?
- If yes: How have you dealt with these challenges?
- If no: What helped the groups to run smoothly?
11. Are all members of the group respectful and do they participate?

12. What could change to make it easier for people to be involved in this group?

Perceptions of quality of training and materials

13. Do you feel that you had the appropriate training to be able to support group members?

- If yes – what aspects of training were most important?
- If no – why not? What skills or information do you feel you are lacking?

14. Did your training enable you to feel confident and organized in facilitating the groups?

Probe:

- Why or Why not?
- What could be improved?

15. What other training do you think would help you to support your group more effectively?

16. Were the training materials you provided with easy to understand and use?

17. Was there anything not included in the training or training materials that you feel is needed to help you perform your role effectively?

Probe for specific topics/issues.

18. Do you feel confident in referring group members to other support/resources when needed?

Adaptations/improvements for intervention

19. What, if anything, would you like to change about the group/s?

Prompt:

- What would you change about how the group is run?
- What would you change about the activities you do?
- Would you change the venue where the group meets?
- Would you change the frequency of meetings?

20. Do you think there may be any issues that we may have not adequately covered in this interview of what could be changed or improved about the way groups work?

21. From your experience how much time per week do you think you spent on following up and home visits for the service users?

22. How do you think we should approach the pre-implementation engagement for the programme? How much of auxiliary social workers time do you think this would take for one group?

23. Why do you think caregivers did not come for the groups?

24. Why do you think few service users came for the group?

25. How could we make sure there are more people in the groups?

26. What parts of the programme do you think are too difficult for service users – e.g. income generating projects?

EMERALD STUDY INTERVIEW SCHEDULE (Incorporating interview questions for Paper 4)

QUESTIONS FOR DISTRICT MANAGERS & COORDINATORS

Aim of the interview

The new Mental Health Care Policy Framework in South Africa embraces the integration of mental health care into primary health care as well as task sharing/shifting to achieve this. In addition to the integration of packages of care for mental disorders which embrace a task sharing approach, health systems strengthening is needed to support these integrated services. *(It may be an idea to ask whether they are aware of the framework when we ask for the interview and to send it to people if they are not).* In the Dr Kenneth Kaunda district PRIME has been working actively with district, sub-district and facility managers to develop a mental health care plan for the integration of mental health services into primary health care. We would like to ask some questions related to systems level issues that could hinder or facilitate the implementation of this plan. This is the focus of the EMERALD project.

No.	Question	Prompts
1. PLANNING & MANAGEMENT		
1.1	In relation to the implementation of the new Mental Health Care Policy Framework, especially integration of mental health into the ICDM through the PRIME project, are there plans in place that address the integration of mental health into primary health care?	<p>Explore:</p> <p>What their knowledge of the mental health policy framework is – whether it has been communicated to them and what they understand their responsibilities to be in relation to developing and implementing the mental health care plan</p> <p>Whether and how the mental health care plan has been initiated</p> <p>What challenges are being faced in developing and implementing the plan</p> <p>Whether and how mental health has been included in the district health care plan</p> <p>What other related plans currently exist at district level that address or are needed to address MH integration</p>
1.2	Are systems for mental health care planning & management at district and provincial level centralised or decentralised ?	<p>Explore:</p> <p>Who or what is mandated with planning & management of mental health care integration</p> <p>How this impacts / will impact on the implementation of the new MHC policy framework</p>

1.3	How are decisions about mental health service planning and budgeting made?	<p>Explore:</p> <p>How this planning and decision making is coordinated with primary health care planning and management</p> <p>How this may impact on the implementation of the new MHC policy framework</p>
1.4	What challenges have you encountered in planning & management for decentralised and integrated mental health care?	<p>Explore:</p> <p>Types of possible challenges: e.g. management capacity, human resource capacity, infrastructure, system challenges, resources</p> <p>Challenges for specific patient groups e.g. those with severe mental illness</p> <p>What is needed to facilitate mental health service planning for decentralised and integrated mental health care as outlined in the new MHC policy framework.</p>
1.5	What are the implications for scaling up the implementation of mental health care plans developed through PRIME-SA to other districts?	<p>Elaborate:</p> <p>For example, in South Africa, we are using the existing HIV counsellors to provide facility based counselling for depression co-morbid with chronic conditions. But the inclusion of this counselling in the role and functions of these counsellors has not been determined at national level yet so jeopardizes the scaling up of this aspect of the SA MHCP</p>
<p>2. CONSULTATION & COLLABORATION</p> <p>The new MHC policy framework emphasises that mental health care is a multi-sectoral endeavour. It also highlights the importance of consulting with all stakeholder in the planning and delivery of mental health services. Now I'll be asking you some questions regarding collaboration and consultation.</p>		
2.1	At district level, how does the DoH collaborate with other sectors to tackle mental health problems?	<p>Explore:</p> <p>Which sectors are considered particularly relevant for mental health care</p> <p>Whether there are mechanisms that facilitate this collaboration</p> <p>What challenges have been encountered in establishing these mechanisms for collaboration</p> <p>What (other) measures can be put in place to facilitate this</p>

2.2	How does the DoH at district level collaborate with other sectors to provide <u>psychosocial rehabilitation</u> for people with severe mental illness, to help them reintegrate into their families and communities?	<p>Explore:</p> <p>What psychosocial rehabilitation services are currently provided, and what the gaps are</p> <p>Who currently provides these services – or who should be responsible for providing them (including inter-sectoral responsibilities)</p> <p>What challenges are faced in providing these services</p> <p>What is needed to ensure that those who need psychosocial rehabilitation have access to it</p> <p>How does this compare to collaboration at the national and provincial levels?</p>
2.3	To what extent are 1) service providers and 2) service users and their families involved in decisions about planning and delivery of mental health care integration?	<p>Explore:</p> <p>How service provider and service user / family participation could improve how mental health care is implemented in the district</p> <p>How DoH managers would feel about working with service providers and service users / families in this way</p> <p>Any specific challenges in working with service users and their families</p> <p>What might help them to work with service providers and service users/ families in this way</p>
3. MENTAL HEALTH CARE PROGRAMMES		
3.1	What do you think are the biggest mental health problems (burden of disease) in the community?	<p>Explore:</p> <p>What they think are the corresponding greatest needs of mental health service users</p>
3.2	Are you aware of any anti-stigma programmes?	<p>Explore:</p> <p>Details of such programmes</p>
3.3	Do you think the MHC policy framework adequately addresses stigma and how to deal with it?	<p>Explore:</p> <p>If not, how they think this could be addressed</p>
3.4	Who do you think should be involved in the planning and delivery of such anti-stigma programmes?	<p>Explore:</p> <p>Whether they think district managers should be involved and, if so, how</p>

		Whether they think service providers and/or service users should be involved and, if so, how
4. HUMAN RESOURCES		
4.1	Is there a coordinating body that is responsible for overseeing the implementation of mental health care integration plans to enact the new MHC policy framework?	<p>Explore whether and how this coordinating body ensures:</p> <p>Ongoing training & supervision of PHC staff in PC101+</p> <p>Ongoing training & supervision of lay counsellors / community staff in adjunct psychosocial interventions</p> <p>Timely appointment of adequate specialist staff</p> <p>Reliable and timely supply of adequate medication</p> <p>Adequate monitoring of quality of services</p>
4.2	What factors (positive and negative) impact on the ability of this coordinating body to fulfil its duties?	<p>Explore the following possible factors:</p> <p>Human resource capacity at management level</p> <p>Coordination between sectors</p> <p>Resources (financial and otherwise)</p> <p>Resistance, lack of buy in</p>
4.3	What challenges are anticipated in establishing district mental health teams as per the mental health care policy framework?	<p>Explore:</p> <p>What they understand the role and functions of these district mental health teams to be</p> <p>What can be done to facilitate this</p>
4.4	How important to the implementation of MHC integration is having staff who are adequately trained and supported in the mental health guidelines contained in PC101+?	<p>Explore:</p> <p>Possible gains or disadvantages of this training</p> <p>Challenges anticipated in rolling out and scaling up this training</p>
4.5	What factors (positive and negative) impact on having maximum coverage of staff trained in PC101+?	<p>Explore the following possible factors:</p> <p>Staff turnover – if so, why, and what can be done about it</p> <p>Sufficient posts – if not, why</p> <p>Recruitment procedures – if these are not efficient, why, and what can be done about it</p>

		Training procedures – if not adequate, why, and what can be done about it
4.6	What factors (positive and negative) impact on using PHC staff and non-professional health workers such as lay counsellors to help identify and provide psychosocial interventions within a task sharing approach?	<p>Explore:</p> <p>Whether their roles in mental health care are acknowledged and accredited</p> <p>Whether there are non-professional workers from other sectors (eg. social development) who could be involved, particularly in providing psychosocial interventions</p> <p>Whether there is a gap between a task-oriented biomedical approach (typical of most busy PHC clinics) and a more patient-centred approach, and what can be done about this</p>
4.7	What factors (positive and negative) impact on having sufficient specialist staff to provide ongoing training, supervision, support and referral services for more complex cases?	<p>Explore the following possible factors:</p> <p>Staff turnover – if so, why, and what can be done about it</p> <p>Recruitment procedures – if these are not efficient, why, and what can be done about it</p> <p>Training procedures – if not adequate, why, and what can be done about it</p> <p>Attitudes of specialist staff to task sharing and their responsibilities within this approach</p>
5. INFRASTRUCTURE FOR MENTAL HEALTH CARE		
5.1	Is the supply of psychotropic medications at district health facilities adequate?	<p>Explore:</p> <p>How existing drug policies impact on the availability and supply of psychotropic medication – and what can be done to improve this</p> <p>How existing supply systems impact on the availability of psychotropic medications - and what can be done to improve this</p>
5.2	What challenges do you anticipate in ensuring that mental health guidelines (PC101, counselling & psychosocial manuals) are available and used at district health facilities?	<p>Explore:</p> <p>What the reasons for these challenges might be</p> <p>What procedures can be put in place to overcome them</p>
5.3	If the mental health care plan includes high intensity counselling provided by trained counsellors, is there	Explore:

	adequate counselling space available at the PHC clinics? Similarly, is there an appropriate venue for psychosocial rehabilitation group meetings?	If not, how this problem can be addressed
5.4	Do you anticipate any other challenges at the facility / clinic level when integrating mental health care into primary health care?	Explore: If yes, what could be done to overcome these challenges

6. CAPACITY BUILDING

6.1 We have been discussing many aspects of health system strengthening, especially focusing on mental health systems. Are there any parts of health system strengthening where you would value (additional) training?

6.2 Please can you rate the following capacity building priorities for your district:

How important is it for your institution to build capacity in each of the following areas?					
1 = irrelevant 2 = not a priority now 3 = important but not a priority 4 = a priority need 5 = an essential need					
	1	2	3	4	5
Mental health policy, planning and programme development					
Mental health policy development or policy review and re-formulation					
Evidence-based mental health care planning					
Mental health programme development					
Planning for a system of mental health in primary care					
Developing partnerships with patients for policy-making and service development					
Human resources projection and cost calculation					
Mental health systems					
Governance of mental health systems					
Mental health system leadership					
Mental health information systems (sufficient indicators integrated into the health information system)					
Mental health system communication					
Mental health system advocacy strategies					

Mental health service implementation					
Training for mental health workforce					
Antistigma campaigns					
Monitoring and evaluation of mental health services					
Developing partnerships with patients to involve in quality control					
Implementation of mental health services in post-conflict settings					
Community-based approaches to mental health care					
Mental health research					
Priority setting in mental health systems research					
Conducting mental health needs assessments					

EMERALD STUDY INTERVIEW SCHEDULE (Incorporating interview questions for Paper 4)

QUESTIONS FOR NATIONAL POLICY MAKERS AND PROVINCIAL PLANNERS

Aim of the interview

The new Mental Health Care Policy Framework in South Africa embraces the integration of mental health care into primary health care as well as task sharing/shifting to achieve this. This is the focus of PRIME, with which you are familiar. In addition to the integration of packages of care for mental disorders which embrace a task sharing approach, health systems strengthening is needed to support these integrated services. This is the focus of EMERALD. *(It may be an idea to ask whether they are aware of the framework when we ask for the interview and to send it to people if they are not).*

EMERALD's objective is to identify system-level challenges to integration. We would like to get your opinions on factors within the institutional, legal and policy contexts of South Africa that will hinder or facilitate the implementation of integration policy and service integration plans.

We would like EMERALD to be useful to the Department of Health in its current task of translating the new mental health policy framework and strategic plan into provincial mental health plans. At the end of this interview, we'd like to get your input on how EMERALD's process and findings could be relevant and useful to you, particularly in terms of capacity building needs we could assist with.

With this in mind, at end of interview, we will ask whether there are any other questions you'd like us to ask as we go forward with these interviews, and any other people you think we should interview. We'll be doing these interviews at district level as well, and extending across both the Department of Health and Department of Social Development.

(As you get to each section, introduce the topic of the section and explain that you'll be asking some questions about that topic).

No.	Question	Prompts	Code
1. LAWS & REGULATIONS relating to MENTAL HEALTH CARE INTEGRATION			
1.1.	What are some of the challenges in translating the Mental Health Care Act (2002), into regulations and policies, and in enforcing these?	<p>Explore:</p> <p>Whether and how there is synergy between the Act and MH policies and regulations</p> <p>What is not sufficiently covered by existing regulations and what they think is the most urgent priority in terms of enforcing the Act</p> <p>Whether the DoH consults other line departments on laws and regulations relating to mental health</p> <p>The relationship of the DoH to regulating bodies for mental health (including coordination and communication)</p>	RoL

1.2	Is there synergy between the MHC Act and laws and regulations involving psychosocial rehabilitation for people with disabilities?	<p>How psychosocial rehabilitation is dealt with provincially</p> <p>How the Department of Social Development will be involved (with the DoH) – e.g. provincial coordinators etc – in the current process of MHC plan development & implementation (what they see as its role)</p>	RoL
2. PLANNING AND MANAGEMENT of MENTAL HEALTH INTEGRATION			
2.1	What challenges do you anticipate in translating the new mental health policy framework into mental health plans at provincial level?	<p>Explore:</p> <p>Pros/ cons of integration – e.g. are there specific patient groups for whom integration may pose challenges (e.g. those with severe mental illness)</p> <p>Who or what is mandated with planning & management of mental health care integration at national / provincial level</p> <p>How planning at provincial level responds to regional and local health (and mental health) needs</p> <p>How decisions about mental health service planning and budgeting are made at national / provincial level</p> <p>Whether and how this planning & decision making is coordinated with primary health care planning & management</p> <p>Whether there are monitoring mechanisms in place to ensure transparency of decisions</p> <p>What plans are in place to facilitate the adoption of the mental health care framework across the 9 provinces</p> <p>The capacity for adopting such plans in each of the provinces, and implementation capacity at district level</p>	<p>R&I</p> <p>T</p> <p>R&I</p>
3. COORDINATION and CONSULTATION			
3.1	What are some of the challenges in the DoH collaborating with other sectors at national / provincial level in the development and	<p>Explore:</p> <p>What mechanisms facilitate this</p>	

	implementation of mental health policies and plans?	<p>What challenges have been encountered in establishing these mechanisms</p> <p>The designated areas of responsibility of the DoH, Depts of Social Development, Labour, Housing , and NGOs in mental health</p>	
3.2	What are some of the challenges in the DoH collaborating with other sectors to plan and manage <u>psychosocial rehabilitation services</u> for people with severe mental illness, to help them reintegrate into their families and communities?	<p>Explore:</p> <p>Whether there are any formal agreements between sectors on provision of psychosocial rehabilitation (e.g with the Dept of Social Development, Dept of Labour)</p> <p>How these challenges could be addressed</p>	
3.3	What are some of the challenges in consulting <u>other stakeholders</u> (e.g. service providers and service users and their families) in decision making about planning and delivery of mental health services at national and provincial level?	<p>Explore:</p> <p>Which stakeholders are involved in decision making and how these inputs are solicited, through which mechanisms</p> <p>What could be put in place to facilitate this</p> <p>How different perspectives and objectives are reconciled</p> <p>Whether the mental health policy framework adequately addresses stigma</p> <p>Whether and how anti-psychiatric stigma efforts are or could be supported at national and provincial levels</p> <p>Whether the integration of MHC into PHC might exacerbate the problem of stigma, and what could be done about it</p>	<p>S</p> <p>S</p> <p>S</p>
<p>4. HUMAN RESOURCES CAPACITY</p> <p><i>(Explain work package two here and ask how Emerald could be helpful in contributing to capacity building)</i></p>			
4.1	What are the priority areas for capacity building at provincial and district levels to develop and implement MHC integration plans?	<p>Explore:</p> <p>What leadership or managerial capacities / core competencies are needed to develop and implement these plans 1) at provincial level (probe for capacity building needs of</p>	EE

		both general health planning staff and mental health coordinators) and 2) at district level (especially probe for the capacity building needs of district health managers for planning and implementing mental health services)	
4.2	What challenges are anticipated in establishing district mental health teams as per the mental health care policy framework?	<p>Explore:</p> <p>What can be done to facilitate this</p> <p>What plans are in place to ensure the identification and implementation of <u>core competencies</u> to facilitate implementation of the MHC policy framework (e.g. diversification of specialist roles, training of non-specialist staff)</p> <p>In relation to establishing these district mental health teams, what is the capacity (authority) of the DoH in accrediting, licensing and regulating mental health training programmes and organisations / professionals that deliver mental health services?</p> <p>How this might impact on the scaling up of district mental health plans developed by PRIME</p>	
5. FINANCING			
5.1	What challenges do you anticipate in the allocation of funds to implement the MHC policy framework at provincial level?	<p>Explore:</p> <p>Whether they think current allocations are appropriate and, if not, what might be done to facilitate / improve this</p> <p>How decisions about allocation of funds for health and mental health are made</p> <p>How transparent the process of resource allocation is in the DoH</p> <p>How equitable is the allocation of public sector funds at national / provincial level and what measures are in place for identifying inequity</p>	<p>R&I</p> <p>T</p> <p>E</p> <p>R&I</p>

		What percent of the national / provincial health care budget is currently allocated to MHC?	
5.2	Whose budgetary responsibility are the people who require <u>psychosocial rehabilitation and community-based services</u>?	Explore: How these funds for psychosocial rehabilitation are allocated Whether they think this allocation is appropriate and, if not, what the barriers are to allocating more funding to community-based services If not appropriate, what are the barriers to allocating more funding to community based services	
5.3	How will mental health services be financed under the NHI?	Explore: The challenges anticipated in moving from the current financing mechanisms to the new NHI (eg purchaser/provider split)	
6. MONITORING & EVALUATION			
6.1	How will implementation of the new mental health policy framework be monitored?	Explore: Who will be responsible for this at provincial level Who is responsible for monitoring mental health <u>services</u> at provincial / district level Whether and how adding MH indicators could assist with M&E processes, and what additional indicators are needed Where and how information about financial and administrative procedures in the DoH is readily accessible	I&I T T
6.2	Are mechanisms in place for overseeing adherence to financial and administrative rules and regulations (i.e. ensuring their enforcement)?	Explore: How do these mechanisms operate If no mechanisms, how this oversight could be facilitated Whether there is evidence showing that such accountability processes are effectively enforced	A A

7. QUALITY ASSURANCE & ETHICS			
7.1	How does the DoH ensure quality of MH services and service user satisfaction?	Explore: The mechanisms available to monitor service user satisfaction Extent of involvement of service users and families in quality control – and if / how this might be improved What procedures are in place for redressing grievances of (a) service users and families, (b) service providers How well the mental health review boards are functioning in each of the nine provinces	R&I RoL
7.2	What policies and mechanisms are in place to safeguard against unethical treatment of mental health service users?	Explore: How these safeguards are enforced Whether there are policies and mechanisms for enforcing codes of professional conduct in MH care	Et
7.3	Similarly, what policies and mechanisms are in place to protect participants in mental health research?	Explore: How these safeguards are enforced	Et

As explained at the beginning of this interview, I'd like to get your input on how EMERALD's process and findings could be relevant and useful to you, particularly in terms of capacity building needs we could assist with?

Are any other questions that you think we could be asking as we go forward with these interviews?

Are there any other people you think we should interview?

What do you think is the best way of feeding back these results back to you, and the best way of acting on the findings?